University of Alberta

Self-Talk: Inner Work of Living with Colorectal Cancer

by

Marilyn Will

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

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ABSTRACT

The purpose of this exploratory qualitative study was to gain understanding of how individuals learn to live with colorectal cancer. Colon cancer is the third most common site of cancer incidence in Canadian men and women. 17,100 new cases (13.5% of all new cases) were expected to be diagnosed in 2000 (National Cancer Institute of Canada Statistics, 2000, p. 19) and mortality was estimated to be 6,500 deaths in the same year (NCIC). In spite of this high level of occurrence, to date, there has been limited nursing research examining any facet of this condition. Attention has not been directed to advancing understanding of the total experience of the person living with colorectal cancer.

The research question that guided this study was: *What is the process people go through as they learn to live with colorectal cancer?* Unstructured, audio-taped interviews with ten men and women, each at different points in their disease trajectory, provided rich sources of data. The guiding principles of theoretical sampling were followed. Through the use of constant comparative analysis, based on the approach of Chenitz and Swanson (1986), a beginning grounded theory was formulated.

Findings from the study revealed a basic social process of 'self-talk' that occurs in response to both 'internal pronouncements' and 'external pronouncements'. Internal pronouncements are ideas expressed to oneself, either independently, or in response to announcements made by others. External pronouncements are declarations made by others, which profoundly influence

the nature and process of 'self-talk'. These pronouncements are definitive, and elicit an internal response. Each pronouncement marks the transition to another phase of the process, affects the nature of the self-talk that occurs, and signifies a turning point that serves as a precursor to subsequent action(s).

The basic social process of 'self-talk' occurs within an eight phase process or trajectory of living with colorectal cancer. The eight phases included: (1) *Acknowledging bodily sensations*: Knowing something is wrong; (2) *Hoping for the best:* Seeking diagnosis; (3) *Wondering about the future:* Receiving the diagnosis; (4) *What am I going to do?* Making decisions/Planning treatment; (5) *Getting through it:* Being treated; (6) *What's ahead?* Waiting and monitoring; for some, (7) *Something is wrong. . . again:* Starting over; and (8) *Getting on with life:* Reflecting/Moving on.

These eight phases take place within two major contexts: relationships with family and friends, and relationships with health care professionals.

Prologue

I would like to share with the reader how I arrived at the point in my professional nursing career where I wished to study the process that one goes through in learning to live with colorectal cancer. My major work has been in the area of nursing education, working with undergraduate students, always with the goal of helping them to gain understanding of what it is really like for the individual to experience any illness situation.

In the course of many clinical practica, I observed that at any one time on an acute tertiary care nursing unit, about one-half of the patients were there with a cancer-related diagnosis: for diagnostic purposes, for surgery, and at times, for palliative care. One of my most favorite units was one focusing on gastrointestinal problems, hence, the predominance of individuals with colorectal cancer.

Further, in regular reading of a variety of nursing journals, I became increasingly aware of the significant amount of research published with respect to several other types of cancers: breast, lung, and prostate, along with the leukemias and lymphomas. Notable by omission was a focus on people diagnosed with colorectal cancer. This stimulated my interest to learn more about this neglected area. Thus, began my journey. I learned much from the ten men and women who participated in this study. They challenged my assumptions, they presented new ideas, and led me to look at the experience in different ways. I am immeasurably changed as a result.

Acknowledgements

I am forever indebted to the ten men and women who have shared their experiences of learning to live with colorectal cancer. One of the motivating factors for them was the sincere desire to assist me in my work with nursing students, so that future nurses would better understand 'what people go through'. It is the desire to honor their stories, which have helped me to persist in this lengthy endeavor.

I owe a very special acknowledgement to my committee members. My supervisor, Dr. Marion Allen, has guided me through the many stages of the research process, always with ultimate patience and genuine interest in doing this work well. She has prompted me to consider alternative ways of understanding the data, and always has provided positive words of encouragement. The gentle influences of Dr. Max van Manen and Dr. Edna McHutchion will be evident to all who know them. Emphasis on the individual experiences, and how these are linked to the lives of those around them, is a tribute to all the committee. Dr. Peggy-Anne Field provided wonderful insights during our final discussion.

Although they would not previously have been aware, I wish to convey my most sincere appreciation to all those nurses I have had the privilege of working with over the years, particularly at the Rockyview Hospital and the Tom Baker Cancer Centre. In addition, coming to know the excellent work of nurses in oncology through ONIGA and CANO has made me a better nurse.

How can I put into words the debt I owe my family and friends? To my husband, Brian, who has been and is always there for me; to my sons and their new families, Carter, Stacey, and AJ, and to Riley and Nikki – I love you all. I could not have done this without your enduring support. Also, to my parents, Mary and Lloyd Mjolsness, who long ago, instilled me with a love of learning, and an ethic of perseverance. Much gratitude is also directed to my colleagues, both at Mount Royal College and the University of Calgary, who have provided constant encouragement.

I am happy to be able to add to what we, as nurses, know about the experiences of those who are in our care.

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Chapter 1

INTRODUCTION

Colon cancer is a leading cause of mortality and morbidity in Canada, with an estimated 6,500 deaths from colorectal cancer occurring in 2000. This compares to an expected 5,500 deaths due to breast cancer and 4,200 deaths due to prostate cancer. Colorectal cancer is the third most common site, for both men and women, surpassed only by lung, breast and prostate cancers. These four types of cancer account for at least 50% of the new cases in each sex. It is estimated that there will be 17,100 new cases (13.5% of all new cases) of colorectal cancer diagnosed in 2000, compared to 20,600 new cases of lung cancer, 19,200 female breast cancer, and 16,900 prostate cancers (NCIC Statistics, 2000, p. 19).

Relationship to aging and gender

Cancer is primarily a disease of older Canadians with 70% of all new cancer cases and 82% of deaths due to cancer occurring among those who are at least 60 years old (NCIC Statistics, 2000, p.9). The incidence of cancer begins to rise after age 40 for men, or 45 for women, doubling with each decade until the age of 80 (Otte, 1988a): mortality rates do not increase until after age 55. Colorectal cancer is a serious concern for the elderly, as 68% of the total cases are diagnosed in males 65 and older, and 75% of female patients are over 65 (Baranovsky & Myers, 1985; De Cosse, Tsioulias, & Jacobson, 1994). Using age-standardized rates, the incidence of colorectal cancer is slightly higher among men than women. "However, because more

Canadian women than men live to advanced ages, the number of new cases of, and deaths due to colorectal cancer among women aged 80 or over exceeds that of men" (NCIC Statistics, 1995, p.66). In general, the numbers of new cases of all cancers and deaths continue to rise steadily as the Canadian population ages (NCIC Statistics, 2000, p. 23).

Incidence and mortality

Currently, one in 16 men and one in 18 women will develop colorectal cancer (NCNC, 2000, p. 10). Since 1985, when incidence rates of colorectal cancer for both men and women peaked, incidence and mortality rates have continued to decline, although at a faster rate for women than among men (NCIC, 2000, p. 9). Such a change is significant, as this may indicate possible gains in the ability to control colorectal cancer. As with most forms of cancer, earlier diagnosis of colorectal cancer leads to improved survival. Declines in incidence and mortality for colorectal cancer in Canada may well be due to reasons similar to those reported in the United States, (Chu, Tarone, Chow, Hankey, & Ries, 1990; Miller et al., 1995). More prevalent use of methods for early detection, leading to more effective treatment, as well as the possibility of lifestyle changes such as improved diet may contribute to the declines in incidence. Kuller and Schoen (1994), commenting on the Chu et al (1990) findings, propose that there are other factors to consider such as "the improved treatment of colon cancer and especially [decreased] mortality associated with complications of surgical therapy" (p. 1554). "Casual

screening is already prevalent in Canada and may have contributed to the reduction in mortality rates" (NCIC, 2000, p. 25).

Survival

Survival from colorectal cancer is more favorable than for most forms of cancer, particularly among men. The five-year survival rate for colorectal cancer is just over 50% for both men (51%) and women (53%), compared to the five-year survival rate for all forms of cancer which is 40% among men and 54% among women (NCIC Statistics, 1995, p. 67). Data on the prevalence of cancer, that is, the number of people alive, at a point in time, who have cancer, indicate that at December 31, 1990 (NCIC, 1995, p. 64) there were 60,900 Canadians living with colorectal cancer diagnoses within the previous ten years. This was exceeded only by those with female breast cancer. "Prevalence is an important indicator of the human suffering and burden of cancer on individuals and society" (NCIC, 1995, p. 64).

Significance of the study

Even though colorectal cancer affects significant numbers of individuals, the amount and type of nursing research focused on this particular diagnosis is extremely limited, particularly in comparison with the research related to other commonly occurring malignancies. The majority of the research and clinical literature accessed at the commencement of this study focused on topics such as epidemiology and pathogenesis, issues in screening and early detection, and the clinical effects of treatment (surgery, radiation, and chemotherapy). People diagnosed with colorectal cancer are

rarely identified as the group of 'choice' for study: more frequently they are simply included as an unplanned subset of a convenience sample. Attention has not been directed to advancing understanding of the total experience of the person living with colorectal cancer.

Examining the qualitative dimensions of learning to live with colorectal cancer has not been a priority for researchers. This is surprising in that nurses work with people everyday who are wondering if they might have bowel cancer, who are undergoing diagnostic tests for certain problems, recuperating from surgery for bowel obstruction, receiving chemotherapy and/or radiotherapy, coping with recurrence of the disease, or are dying from colorectal cancer. If nurses are committed to working with men and women to enhance quality of life, it is essential to explore the actual experience of those who are continuing to live with colorectal cancer, in order to expand the knowledge foundation for nursing.

Purpose of the study

The purpose of this exploratory qualitative study is to investigate the experience of individuals who are learning to live with colorectal cancer. It is hoped that comprehensive understanding of the process one "goes through" as one learns to live with this condition, will assist all health care professionals in their common goal of facilitating optimum health for each person. Obtaining a better grasp of the issues for people with colorectal cancer is the first level of investigation, from which further studies will evolve.

Chapter 2

REVIEW OF THE LITERATURE

Prior to commencing this research study, I examined a variety of literature sources in order to determine the range of topics related to colorectal cancer that had been addressed. Consistent with the view of Burns and Grove (1999), this review "was a means of making the researcher aware of what studies have been conducted" (p. 107). Similarly, at the completion of the study, I again returned to the literature in order to situate more appropriately my research into this body of work. These examinations of the literature revealed that persons with colorectal cancer are under-represented in nursing research on cancer.

Search of databases

A computer search of several major databases (CINAHL: Cumulative Index to Nursing and Allied Health Literature, 1982-2000; MEDLINE, 1980-2000; Cancer Lit, 1990-2000; and Psych Lit, 1988-2000), used the key words of: "cancer, colon, colorectal neoplasms, and research". This search resulted in the location of over one million papers when the broad category 'cancer' was used. When the search was narrowed through the addition of the other terms, the literature became much more restricted and more manageable. In reviewing over 600 research articles that were designated as involving colorectal cancer it was discovered that many of these studies only coincidentally included people with colorectal cancer. It was evident that the primary focus of the inquiry was not on this particular diagnostic group. This

was surprising given that colorectal cancer is one of the most common types of malignancy in North America. In an attempt to further limit the literature and to focus on work that dealt only with colorectal cancer, 83 nursing research articles, as well as 94 review articles were selected for in-depth review. This representative literature provided an overview of the range of topics that relate specifically to colorectal cancer, and served to clarify the research question. The majority of the review articles came from medicine, with the disciplines of nursing, psychology and social work represented in much smaller numbers. Content areas most frequently addressed included: the overall management of colorectal cancer, specifically, epidemiology and pathogenesis, screening and early detection; impact on the elderly population, therapy, and quality of life and other psychosocial issues.

Management of colorectal cancer

The work on *epidemiology and pathogenesis* of colorectal cancer has focused primarily on increasing understanding of the origins and the development of this type of cancer. This work has subsequently led to distinct recommendations regarding the prevention of colorectal cancer (American Cancer Society, 1986; Burkitt, 1971; Connors & Bynum, 1991; Fitzsimmons, 1992; Fitzsimmons & Fales, 1993; Guthrie, Hines & Mazier, 1992; Taylor & Moffet, 1994; Saddler & Ellis, 1999). More recently, the discovery of genetic markers specific for identifying those persons at risk for colorectal malignancy offers much promise for early detection (Boguski, 1991; Glaser, 1998).

Controversy over the most appropriate *screening and early detection* measures for colorectal cancer for "average" risk, asymptomatic individuals continues as experts weigh the options of the digital rectal examination, fecal occult blood testing, sigmoidoscopy, and colonoscopy (American Cancer Society, 1999; Connors & Bynum, 1991; Fitzsimmons & Fales, 1993; Guthrie, Hines & Mazier, 1992; Kemppainen, Hakkinen, Raiha, Pomoell & Sourander, 1994; Levin, 1992; Lieberman, 1994; Neugut, 1993; Squillace, Berggreen, Jaffe, Fennerty, Hixson, Garewal & Sampliner, 1994; White & Spitz, 1993; Winawer, Fletcher & Miller, 1997). Much of this controversy centers on cost-benefit issues. Criteria used to help establish the cost-effectiveness and cost-benefit of screening procedures relate to factors such as availability, safety, patient compliance, comfort, cost, accuracy, and comparability (Podolsky, 2000; Simon & Fletcher, 1998; World Health Organization cited in Connors & Bynum, 1991). No articles were found in which the experience of receiving these diagnostic procedures was discussed; nor was this included in the discussion of cost versus benefit. In fact, discussion by individuals on their perceptions and feelings regarding risk of colorectal cancer was non-existent.

Various aspects of the classic *treatment modalities* (surgery, radiotherapy and chemotherapy) were the subject of many articles written mainly by physicians (e.g. Farniok & Levitt, 1994; Forman, 1994; McGinnis, 1994; Saddler & Ellis, 1999). Although primarily dependent on the pathological stage of disease presented, the definitive treatment for colorectal cancer remains surgery. The type of surgery performed will depend on the

surgeon's expertise and personal preference; the tumor site, size, and histological grading; whether or not perforation or obstruction is present; evidence of spread or resectability; the goal of cure or palliation; bowel preparation before surgery; and the sex, age, and health status of the patient (Wicks, 1986). These considerations have not changed. Improved surgical techniques using stapling devices and colonoscopy have greatly reduced the incidence of ostomy surgery, a fear of which may contribute to delay in seeking attention for symptoms (Coe & Kluka, 1988; Otte, 1988; Thomson, 2000). The identified papers provided excellent overviews of the technical perspectives of surgery and the associated physical care, however, there were no articles that examined the process of learning to live with a diagnosis of colorectal cancer and the related aftermath.

Both radiation therapy and chemotherapy are used as adjuvant treatments to primary surgical resection to prevent local recurrence. These two treatment modalities are given either alone or combined with other modalities for selected patients to try and achieve a cure or for palliation of symptoms when cure is not feasible. As was noted above, there was no literature found that contained the actual stories of these men and women undergoing adjuvant treatment.

The majority of articles surveyed were written as descriptive summaries, or as reports of clinical trials associated with particular treatment protocols. While these are indispensable in the overall informed management of the disease of colorectal cancer, how people deal with this event in their life

is as yet only minimally understood. Picherack (2000), commenting on the quantity of research done with survivors of breast cancer, writes: "I wonder if these same findings would be true of individuals experiencing other types of cancer?" (p. 52).

Colorectal cancer and older people

As with many types of malignancy, colorectal cancer is most common in people aged 65 years and greater. It was postulated that the impact of the diagnosis and special needs of this large group might lead to research that focused on older adults. However, in the initial searches, only six reports were located that paid particular attention to *the older person.* In five out of the six papers, only people diagnosed with colorectal cancer were sought as participants, perhaps indicating awareness of the incidence of this form of cancer in the elderly. Among the specific topics studied were: the relationship between health perception and participation in cancer screening procedures (Zabalegui, 1994); behaviors of health-care providers and health-care organizations which influence individual health perceptions (Faithfull, 1994); knowledge of colorectal cancer (Weinrich, Weinrich, Boyd, Johnson, & Frank-Stromberg, 1992); variations in initial presentation between different aged groups of elderly (Curless, French, Williams, & James, 1994); variables associated with nonreceipt of definitive therapy (Goodwin,Hunt, & Samet, 1993); and issues relevant to guide cancer nursing planning for the geriatric oncology population (Boyle, 1994). Again, there were no studies that

comprehensively addressed the experience of older persons living with colorectal cancer.

Psychosocial aspects of chronic disease/cancer

There is a vast literature base concerning the many psychological aspects in cancer care: *psychosocial aspects* of living with a chronic illness such as stress, coping, and adaptation; communication issues within the family and with health professionals; social support; sense of control (self-efficacy); self-esteem; the trajectory of chronic illness; and assessment of quality of life. In particular, the global concept *'quality of life'* has received an impressive amount of attention over the years since the question was raised in a two-page paper, "Can quality of life be evaluated?" (Engquist, Davis, & Bryce, 1979). Although there is still no universally accepted definition of quality of life, it has been customary to consider such major factors as: (1) functional capacity (the abilities to perform activities of daily life, social function, intellectual function, emotional function, and economic status); (2) perceptions (levels of well-being and satisfaction with life); and (3) effects of symptoms of disease and treatment side effects (Aaronson, 1990; Cella, 1994; Osaba, 1991). Cohen, Mount, and MacDonald (1996) state, "We believe and others concur that it is premature to conclude that we have a clear and complete working understanding of what constitutes quality of life".

It was demonstrated by De Haes and van Knippenberg (1985), that only a small portion of the instruments applied to quality of life of oncology patients research dealt with the broad spectrum of factors, "particularly

disregarding the social sector in comparison to somatic functioning and mood" (p. 812). This tendency has changed gradually in the intervening years, with much of the current emphasis on a comprehensive view of the components of quality of life. Muthny, Koch, and Stump,(1990) expressed the view "that survival rates and symptoms are no longer considered sufficient criteria for [judging] the effects of medical treatment. . . . Rather, there is an increasing focus on the 'quality of survival' " (p. 145). Accordingly, the main functions of the quality of life research in oncology are: (1) evaluating therapies--including psychosocial criteria as well as physical health dimensions; (2) giving a better basis for decisions between competing treatments by including criteria of quantity *and* quality of survival; and (3) helping to develop more focused and more efficient ways of psychosocial care for patients with malignant diseases (p. 145). Despite some common ground on how quality of life research can inform oncology there is still the tendency to use ad hoc questionnaires to assess this area. The caution that Fava (1990) made still holds. He cautioned researchers to avoid "miscommunication, random effort and faulty reasoning . . . in the illusion of simplicity" (p. 70). Fava noted that well validated rating scales were essential. However as a consequence of the ad hoc use of instruments, there is insufficient research in this area on which health professionals can base their recommendations to people with particular diseases.

Researchers, who have examined psychosocial issues related to cancer, have predominantly obtained their research sample from the total

population of people with a cancer diagnosis (Cunningham, Lockwood, & Cunningham, 1991; Ell, Mantell, Hamovitch, & Nishimoto, 1989; Ell, Nishimoto, Mediansky, Mantell & Hamovitch, 1992; Fitch et al.,1997; Halstead & Fernsler, 1994; Kelman & Minkler, 1989; Northouse & Northouse, 1988; Northouse & Wortman, 1990). However, there have been exceptions to this. Padilla and colleagues studied the impact of colorectal cancer and radiation treatment on key dimensions of health quality of life by comparing this group to others undergoing similar treatment (Padilla et al., 1992). The responses received suggested "that maintenance of health quality of life is an ongoing adaptive process" (p. 1450). This conclusion is supportive of a plan to study the process of learning to live with colorectal cancer.

Galloway and Graydon (1996) examined the relationships between uncertainty, symptom distress, and discharge information needs after a colon resection for cancer. Data collected from 40 individuals using three instruments, at 72 hours prior to hospital discharge, indicated moderate levels of uncertainty, low levels of symptom distress, and a moderate number of discharge information needs. An increase in uncertainty was significantly associated with an increase in discharge information needs, however the researchers also noted that the uncertainty scale had inadequate established reliability. In a similar vein, Sahay, Gray, and Fitch (2000) conducted telephone interviews of 20 patients with colorectal cancer attending a follow-up clinic. They talked with participants about their satisfaction and perceptions regarding quality of care, information received, involvement in decision

making, and long-term management of the illness. The findings indicated that patients were satisfied with their treatment, including the quality and timeliness of the information they received, the quality of their healthcare, and the level of involvement in decision making. However, some patients were dissatisfied with information concerning long-term management of their illness. This was especially true of those who received a colostomy. The open-ended questions provided comprehensive data, although it is possible that the range of responses may have been limited due to the structured nature of these questions. What the study did not address was how these people learned to live with or manage their disease.

Three U.S. studies focussed on the demands of illness (DOI) and spiritual well being in people with colorectal cancer. Using both a descriptive correlational and comparative design, Fehring, Miller and Shaw (1997) studied 100 elderly people with a mean age of 73 years, diagnosed with lung, breast, or colon cancer. Conclusions were that 'intrinsic religiosity and spiritual well being are associated with hope and positive mood states in elderly people coping with cancer" (p. 663). Subsequently, Fernsler, Klemm, and Miller (1999) observed that a greater degree of spiritual well being may help to mitigate the DOI imposed by colorectal cancer. The DOI were greater among men, the youngest subjects, those who received treatment in the previous two months, and those who reported decreased activity, metastatic disease, and/or terminal status. Women reported significantly greater spiritual well being than men. Similarly, Klemm, Miller and Fernsler (2000), based on

data from 121 people who participated in an online colorectal support group, found that time since treatment, perception of illness, and activity level accounted for 45% of the variance in DOI scores. They also noted that 'colorectal cancer imposed significant psychosocial and existential concerns on respondents, especially the youngest age group" (p. 633).

In a European follow-up study of persons with cancer, Courtens, Stevens, Crebolder, and Philipsen (1996) found a positive relationship between the types of social support and quality of life, however the researchers were not able to make definitive statements on the causality of these relations. Even though patients' functioning improved and the amount of physical complaints decreased over the year after diagnosis, psychological complaints and the global evaluation of life did not change significantly over time. The researchers acknowledged that this group of people all had a relatively good prognosis, and data were obtained when they were in remission or in a treatment-free period. No data, however, were provided for the various subgroups that made up this study (21% had colorectal cancer) so it is unclear whether there were differences between the various diagnostic groups.

Quality of life was also assessed in persons with a stoma (Nugent, Daniels, Stewart, Patankar, & Johnson, 1999). No information was provided related to the medical diagnosis of the participants so an assumption could be made that many of these people would have been diagnosed with colorectal cancer. Data from 70% of the eligible patients, indicated that many people

coped extremely well with a stoma; however, some individuals experienced considerable difficulty and distress. The authors suggest "improved preoperative assessment and counseling with longer follow-up would be helpful . . . and would contribute to improvement in the quality of their lives" (p. 1569). Noting that psychosocial intervention therapies are available in order to enhance quality of life, but that strategies that focus on physical aspects have received less attention, Courneya and Friedenreich (1997) examined the beliefs of 110 survivors of colorectal cancer and the determinants of exercise in cancer treatment. Significant findings were that "exercise prediagnosis will be the best predictor of who will exercise during cancer treatment" (p. 1720), and "patients with cancer view exercise for what it can do in terms of helping them cope with their cancer treatment" (p. 1721).

In summary, although there are studies that focus on various aspects of living with colorectal cancer, there were none found that provided a comprehensive picture.

Research question

It is apparent from this review of the literature that little is known about how individuals live with their colorectal cancer and the concerns and issues with which they must cope throughout this experience. Obtaining a better grasp of the process that people go through from the time of diagnosis of colorectal cancer to the time that they are told that they are '"disease free" is the necessary first step in obtaining this understanding. The research

question, therefore, that guided this study was: *What is the process people go through as they learn to live with colorectal cancer?*

Chapter 3

METHOD

Research Design

At the time of commencing this research, there were no nursing studies located that examined the person's experience with colorectal cancer. A qualitative approach then, was chosen as most appropriate since "Qualitative methods can be used to uncover and understand what lies behind any phenomenon about which little is yet known" (Strauss & Corbin, 1990, p. 19). Given the paucity of research related to how one learns to live with colorectal cancer, it was decided that an exploratory study would be undertaken, in order to gain understanding of the underlying process. As the research question posed was related to the process one goes through in order to learn to live with colorectal cancer, a grounded theory method was selected. A goal of the grounded theory approach is to generate theory from data collected about a substantive area of study (Glaser, 1992).

The method of grounded theory was originally developed by Glaser and Strauss, in the 1960's. Influenced by the symbolic interactionist perspective, Glaser and Strauss (1967) emphasized the importance of theory which is grounded in reality, recognized that the nature of experience is continually evolving, and that persons are active in shaping the worlds they live in (Strauss & Corbin, 1990). Grounded theory research is aimed "at understanding how a group of people define, via social interactions, their reality" (Stern, Allen, & Moxley, 1982, p. 203). In grounded theory, the

research problem is discovered, as is the process that resolves this problem (Glaser, 1992). The researcher using the grounded theory method moves into an area of interest without a specific problem in mind. It is essential not to force the data with a preconceived notion of the problem. Since the initial work by sociologists Glaser and Strauss (1967), many nurses researchers have used the methods of grounded theory to gain understanding of people living with a wide variety of chronic diseases (Morse & Johnson, 1991; Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, & Weiner, 1984; Strauss & Corbin, 1990; Woog, 1992). In this study the practical guidance, as provided by Chenitz and Swanson (1986), has been extremely valuable to me as researcher.

Participants

Both purposive and network sampling techniques were implemented initially to access suitable participants. The process of sampling began with a major urban cancer center. The nurse-coordinator of the GI clinic provided me with a list of individuals who had attended the clinic based on the following inclusion criteria: diagnosed with colorectal cancer, at any stage of treatment, adults who speak and understand English, live within driving range of a large urban center, willing to participate in this study, and able to commit the necessary time for interviews. The decision to interview people at any stage of their disease was made in order to access the broadest range of experiences. Only names and phone numbers were included on the list given to me by the nurse in the clinic: there was no discussion of particular

background information. Certain gate keeping activity occurred by others at the centre, resulting in some limitations in the theoretical sampling that could take place. The effect of these limitations on the emerging theory will be addressed in chapter six.

Participants were selected sequentially, consistent with the principles of theoretical sampling. Theoretical sampling is the process whereby the researcher simultaneously collects, codes, and analyzes data and then decides what data to collect next. The goal is to fill in thin areas and extend the substantive theory. Theoretical sampling is based on the need to collect more data to examine categories and their relationships, and to assure that the notion of representativeness exists (Munhall & Oiler, 1986). The full range and variation in a category is sought to guide the emerging theory (Chenitz & Swanson, 1986). As an example, when I noted that several early participants were generally of the mid-range related to socioeconomic status, a plan to identify someone who would represent a different status was initiated. Similarly, individuals were sought who varied in terms of marital status, age, level of education, employment status, and types of cancer treatment received. As well, when it was noted that patients were diagnosed following expressed concern about specific bowel symptoms, individuals who had a differing diagnostic history were discovered.

Participants involved in the study were five men and five women who ranged in age from 54 to 71 years, which is typical of the age range in which bowel cancer is normally diagnosed. The time since initial diagnosis with

bowel cancer ranged from a few months to eleven years; with the average being 3.1 years. Participants received a mix of treatment regimes: some required only surgery; some received both surgery and chemotherapy; and others underwent surgery, chemotherapy, and radiotherapy. Most people were married; some were single. Six were retired; two were employed; and two did not work outside the home. Socioeconomic status varied considerably, largely related to the educational level attained. Five individuals achieved post-secondary levels, two completed high school, and three did not complete high school. One person has died; one person is experiencing a recurrence; and eight have now resumed their day to day activities. As this research took place in one community, only general data have been presented so as to ensure the anonymity of the participants.

Data collection

Data collection occurred through face-to-face unstructured interviews, which were audiotaped, and then transcribed verbatim. Participants were invited "to talk about their experience with colorectal cancer" and to begin wherever they would like to tell their story. The view that "no detail is unimportant" was conveyed verbally. The researcher acknowledged the hesitancy one might have in speaking about such a private topic as "bowel stuff"; simultaneously emphasizing that this is a very common cancer. In all instances, the interviews took place in a comfortable setting, such as at the kitchen table or in the living room, often with the participants sharing a pot of tea. Most informants began eagerly providing their history in terms of

symptoms and dates of particular treatments. This established a context within which one could better understand events and related comments. Background data were obtained either near the beginning or at the end of the time together (Appendix B). First interviews were usually about one and one-half hours long; second interviews were shorter. The purpose of the second interviews was to clarify, elaborate, and/or confirm data, interpretations, and conclusions (Field & Morse, 1985). Specific questions for the second interviews were derived from the ongoing analysis of the data.

Data analysis

Integral to grounded theory is the requirement that the researcher engage in constant comparative analysis of the data. The method is circular, allowing the researcher to change focus and pursue leads revealed by the ongoing data analysis (Hutchinson, 1986, p. 119). It is necessary to compare incident with incident, incident with category, and finally, category with category or construct with construct. The aim is to distinguish similarities and differences among the data.

Data were compared between and among participants and analyzed using the methods of Glaser and Strauss (1967), Glaser (1978, 1992), as interpreted by Chenitz and Swanson (1986). Even in the initial proof reading of the transcripts, the researcher begins to "get a sense of the interview as a whole" (Sandelowski, 1995, p. 373). The grounded theorist starts without any preconceived codes. The initial phase of data analysis, known as open coding, began with line by line reading of the interview transcripts. Words that

would be descriptive of the content, such as "*pain in the rectal area*", were written in pencil in the right hand margin. In many instances, these would be 'in vivo' or substantive, using the exact words of the participant. These code names, such as "initial symptoms', related to phrases or sentences that captured common ideas, or themes. Transcripts were read several times over, leading to recognition of the pattern of a trajectory of illness (Corbin & Strauss, 1992). As the substantive codes were identified, there were clusters of codes that were linked together as categories. The substantive codes "conceptualize the empirical substance of the area of research" and are different from the theoretical codes (Glaser, 1978, p. 55). Further analysis of the substantive codes led to development of theoretical codes. The researcher designated the terms to be used to describe phenomena observed in the data. Continuing the example, "rectal pain" was grouped with other sensations or observations, to become 'initial symptoms'. Cognitively attending to 'initial symptoms' was identified as occurring for each participant, and led to the theoretical code of 'knowing something is wrong'.

By comparing similar episodes, the basic characteristics of a category were defined. Phrase by phrase, similarities and differences of categories were noted. The end of one category and the beginning of another began to be distinguished, as well as how each category related to the others. The aim is to fully develop each category.

As conceived by Glaser (1978), and elaborated by Chenitz and Swanson (1986), the notion of the '6 C's' (cause, consequences, covariance,

contingencies, context, and conditions' (p.41)) was helpful in conceptualizing the basic social process. For example, regarding 'cause', one could say, " self-talk occurs in order to help a person try to make sense of what is happening to him/her"; the 'consequences' of 'self-talk' led to the individual seeking help or undertaking some action; 'covariances' were considered for situations where 'bowel symptoms' were not the first sign, but rather, sensations of discomfort and pain were noted. There were no situations where the basic social process of 'self-talk' did not take place, although some individuals engaged in more 'self-talk' than others. It was also apparent that the nature of 'self-talk' changed over time, within a trajectory framework.

The technique of memo writing in order to capture ideas or reflections as they occurred during the analysis was an essential aid in the conceptualization of more abstract thoughts. Hutchinson (1986) writes: "Memoing is a vital part of this process, permitting the researcher to quickly and spontaneously record his or her ideas in order to capture the initially elusive and shifting connections between the data. . . documenting the thinking process" (p. 123). Numerous memos were written on a great variety of topics: ideas for theoretic sampling, thoughts on how categories linked, suggestions for follow-up on certain details, and questions emerging from the data. A guiding principle was ". . . to stay conceptual. Memos. . . pertain to the concepts that represent abstractions of incidents, events, and happenings" (Strauss & Corbin, 1990, p. 203). For example, one memo that addressed the notion of the wives of participants making the doctor's appointment for the

husband, led to the follow-up questions of women participants about the process they used to make similar appointments.

At a later point in the analytic process, a storyline memo (see Chapter 4) was written in order to better connect the various categories that had been identified. Through compiling previous memos and thoughts into a story, one comes closer to identifying the central idea of the phenomenon under study (Chenitz & Swanson, 1986).

Diagrams are visual representations of the relationships between concepts and of movement through the process (Chenitz & Swanson, 1986,p. 117). A form of diagramming was used to depict the trajectory of each participant's cancer experience. This record provided a chronological ordering of significant events in the mind of the researcher, and a way of tracking the advent of particular categories for an individual. The record also proved useful in structuring the substantive theory that emerged from the data.

Methodological rigor

Evaluating rigor in qualitative research is the assessment of trustworthiness or "how a researcher can persuade his audience that the research findings are worthy of attention" (Lincoln & Guba, 1985, p. 290). Criteria for establishing the trustworthiness of interpretive research include the requirements for credibility, applicability (fittingness), dependability (auditability), and confirmability.

"The *creditability* of qualitative research is enhanced when the investigator describes and interprets their own behavior and experiences as

researchers in relation to the behavior and experiences of participants" (Sandelowski, 1986, p. 30). The researcher must attempt to suspend or lay aside what is known about the experience being studied. Bracketing entries included my perspectives as a nurse educator who had many observations of individuals experiencing colorectal cancer in the acute care setting, as well as being a relative of someone with the condition. In addition, my beliefs, values, and preconceptions about the research topic were documented. For an example, one of my beliefs was that cancer must always be a devastating experience. This writing was done prior to interviewing the first participant. The aim of bracketing is to provide a clear picture of the researcher "as the instrument of data collection and the center of the analytic process" (Patton, 1990, p. 46), in order to detect possible influences on the research process. It was a constant challenge to remain in the 'researcher' role versus lapsing into more of a 'nurse' role.

The criterion of *applicability (fittingness)* is used to establish the degree to which what is thought to be understood is actually being conveyed. In this study, data were obtained directly via the participant's words rather than using an instrument or scale. A critical first step was the comparison for accuracy of the transcript to the audiotaped interview. At the same time, margin notes were added which described nonverbal activities and important recollections. The use of theoretical sampling facilitated obtaining data which were representative of the scope of experience for individuals with bowel cancer. The notion of *saturation,* referring to the completeness of all levels of codes

when no new conceptual information is uncovered in the ensuing data, was influential in determining the final number of participants. When the findings from a study can "fit" into contexts outside the study situation, and when an audience views the findings as meaningful and relevant in terms of their own experiences, a study has met the objective of *fittingness*. Summary type questions were used during the later interviews in order to obtain responses that either confirmed or refuted analyses made. The use of *member checks* (Lincoln & Guba, 1985; Field & Morse, 1985) was also incorporated when portions of the findings were provided to selected participants and academic colleagues for critical feedback. Member checking is directed at a judgment of overall applicability. Those who read segments of the analysis and subsequent theory development validated the content of the writing as being similar to their experience.

The major strategy for establishing *dependability* is the use of an *audit*, which suggests that another researcher could arrive at comparable conclusions given the same data and research context (Lincoln & Guba, 1985; Yonge & Stewin, 1988). Practices such as: regular consultation with my thesis advisor; review of the emerging analysis by the thesis advisor; and the writing of research journal entries were maintained. In this journal, documentation of procedures observed during data collection and analysis, methodological decisions and questions related to the emerging theory were noted.

Confirmability is achieved when auditability, credibility, and applicability are established. Confirmability refers to the findings themselves, not to the subjective objective stance of the researcher (Sandelowski, 1986). Careful adherence to the previously discussed recommended practices in order to achieve accepted criteria for 'establishing trustworthiness' (Lincoln & Guba, 1985) was maintained throughout the study. It is my hope that the reader of this report will be persuaded that the principles of 'good science' have been followed.

Protection of human rights

The proposal for this study was approved by the University of Alberta Faculty of Nursing Ethics Review Committee, who determined that satisfactory measures for the protection of human subjects were included in the study design. In addition, because the actual data collection was to occur in another city, the proposal also was reviewed by the ethics committee at the cancer center, as well as the local university Conjoint Medical Ethics Committee.

Potential participants were identified by the nurse coordinator of the cancer center gastrointestinal clinic; names and telephone numbers were provided. The researcher called individuals to discuss the study and to see if they were willing to participate. If there was agreement, arrangements were made for an interview at a mutually convenient time and place. All participants suggested that the interview take place in their home. The process of obtaining informed consent was initiated at the beginning of the meeting, with

the aim of ensuring that the individual would understand clearly the purpose of the interview. A copy of the signed consent form (see Appendix A) was given to the participant, and the researcher retained one. People were provided with the telephone number of the researcher and the thesis supervisor for any questions or concerns related to the study. Willingness to participate in a second interview was interpreted as ongoing consent.

While there were no anticipated direct risks to the individuals associated with participation in this study, it was recognized that some might become upset or distressed by thoughts or feelings arising as a result of interview discussions. Participants were provided with the name and phone number of a psychologist at the cancer center if they wished any counseling. Several participants commented on their satisfaction in, hopefully, assisting others by giving their point of view, or by 'teaching' others about their world. The benefits of this study may be viewed in terms of the advancement of knowledge about the process of learning to live with colorectal cancer, and subsequent use of this knowledge to improve nursing care for these individuals.

A number of procedures were followed for the protection of a participant's identity. Audiotapes and transcribed interview data were kept by the researcher in a locked file cabinet. Data were only accessible to the researcher, her supervisor, and the transcriptionist. All information about the participants was kept in confidence. Care has been taken to conceal identities. Each participant, as well as the various physicians mentioned, was

assigned code names. The list of code names, phone numbers, addresses, and signed consent forms were stored separately from the transcriptions. The remainder of the raw data will be retained by the researcher in a locked location for at least seven years. In any writing, a generalized description of the entire group of participants will be provided, rather than of specific people. Excerpts of data may be used in reports but only code names will be included.

At the outset, it was determined that if, during the course of this study, information regarding unethical or unsafe practice by a health care provider was disclosed, the situation would be discussed with the participant. Action would only be taken in accordance with the person's wishes. There were no instances of this type of occurrence.

Chapter 4

TELLING THE STORY

The objective of this research was to develop a grounded theory that explained the patterns common in learning to live with bowel cancer. What makes a theory 'grounded' is that it is situated in and emerges from the data, that is, the experiences of people who share particular circumstances. In this chapter, then, in order to provide the structure for the developing theory, I will tell the story of the ten men and women as they were learning to live with bowel cancer. The substantive theory will be presented in Chapter 5.

Analysis of the data obtained during unstructured interviews of these participants revealed a basic social process of 'self-talk' that occurs in response to ideas expressed to oneself or in response to announcements made by others. These definitive announcements to self or by others mark the transition to another phase of the process of learning to live with colorectal cancer. The phases represent a trajectory, from the beginning awareness of a problem, to continuing to live or to die, and thus serve as a framework within which self-talk occurs. The contexts of relationships with health care professionals, as well as connections with family and friends, were found to be highly significant.

Grounded theories are guided by the assumption that people do order their world and so the story is told around the categories that emerged from the data. As the categories were examined, the following storyline memo was constructed in order to describe the central ideas.

STORYLINE MEMO: LIVING WITH COLORECTAL CANCER

I looked at the toilet tissue with bewilderment. This has never happened before. Usually I never pay much attention. I suppose that maybe I should pay more attention—what does this mean? For today, I'm not going to say anything about it. . . maybe it is just a temporary thing. No sense worrying Wendy. I'm not sure if I should be worried or not. . . might be nothing. Likely just hemorrhoids—must drink more water.

I begin to pay attention to what was happening with my bowel movements. Yes, there were changes. And yes, there is often some blood. I am so busy with my work, pushing myself to meet deadlines, attending to the multitude of details entailed in running my business. There just isn't time to get into this sort of talk with Wendy. And I'm 100% sure, that once I say anything to her, she will insist on a visit to the doctor. . . and the time just isn't "right'. Besides, I'm often so tired at night; it's all I can do to stay awake after supper. . . and I really don't have any pain, not real pain anyway.

Time passes. . .

I know that I'd better talk to Wendy. I know that she will be very upset, to say the least, if I don't say anything. . . and I am beginning to worry about what is going on.
It isn't much 'fun' to talk about—who wants to know the details around this sort of thing—sort of disgusting. Much to my surprise, once I blurted out my observations to Wendy, she looked at me, and said, "Well, I've been wondering. . . I noticed what looked like dark blood a few times when I've cleaned the toilet." As I predicted, the next day, Wendy called the family doctor for an appointment. He said he could see me in two days, at about 4:00 pm. I appreciated that this near the end of my workday. . . it was a busy time of the year.

It has been a long time since I last went to the doctor. And then it was just for a bad chest cold, and we were leaving soon on a holiday. I watched the clock in the waiting room, as the minute hand circled – slowly it seemed. Eventually, my name was called. Wendy waited. It certainly was embarrassing talking about this to anyone—even the doctor. I know in my head that I shouldn't feel this way, but it did seem sort of 'private'. As I talked, the doctor looked over the notes in his file. "Looks like it has been awhile since you were here Joe. . . haven't had a <u>complete</u> checkup for over two years". . . I knew what <u>that</u> meant. In fact, <u>that</u> was exactly why I didn't like going to the doctor! Guess there was no escaping this time.

The physical examination followed, including the dreaded DRE—the digital rectal exam. The doctor didn't say too much during this time. He indicated that he would meet me in his office, after I redressed.

"I am a bit concerned Joe. I could feel a slight thickening along the bowel – would be advisable to do a few more tests, see a specialist in this area. . . could be a tumor."

I gripped my hands together, and tried to focus on the doctor's words. "What does that mean?" Dr. White said, "Well, it could be nothing. Or it could be a mass that must come out. It will depend on what these tests show. Let me give Dr. Shaw a call right now. . . maybe they can fit you in, since you are already here." I barely heard him, as the thoughts were whirling in my head: must be bad, why is he acting on this so quickly, what will they do, always been healthy, how will Wendy react, too busy at work, feel fine really, is he talking about cancer, didn't mention the word, I'm probably just overreacting. . . Then Dr. White was saying, ". . . his office is just on the second floor. You might have to wait for awhile, but they can see you today." I felt as though I swayed as I rose from the chair. I needed to talk to Wendy. What does all this mean?

The next few days seemed to go by in a blur—after the initial visit to Dr. Shaw, there was the sigmoidoscopy, then the preparation for the colonoscopy, then the colonoscopy. Dr. Shaw didn't 'pull any punches', "I think you have cancer there." By this time, I thought I was quite prepared to handle whatever the doctor told me. Much to my surprise, tears welled up in my eyes, especially as I looked at Wendy, and I gingerly asked the Dr., "Well, how long do I have?" I realized that I knew very little of what to expect. .. I had always considered myself a very healthy person. I thought that I had followed a healthy lifestyle: don't smoke, don't drink that much, maybe overeat once in awhile, try to get some exercise at least once a week. How could this be happening? I have a lot to do yet! My newest grandchild is only six months old.

The date for the operation is set for March 25—two months from when I first visited Dr. White. I'm not at all sure that I can handle the wait. My emotions are running the gamut, from feeling "I can beat this thing", to frustration and anger that this assault on my healthy body can occur without my agreement, to utter despair that my "days are numbered". It seems that each time I talk to someone, there are new bits added to the puzzle. How can a puzzle be solved if the number and shape of the pieces is ever changing? Wendy and the kids really help to 'keep me sane'—they're always so upbeat, and positive in their outlook. It was hard to tell with Dr. Shaw. Part of this may be due to the fact that I've only seen him twice—seemed like a 'decent fellow'—but he certainly was blunt. Was this his way of preparing me for the 'worst', or is he so used to giving this type of information that he's forgotten the impact it has on the person sitting across the desk? The one good aspect of having to wait this long is that Wendy and I have time to review our wills.

Finally, March 25 arrives. I wished I had taken the sleeping pill that was suggested. The nurse entered saying, "Better get this show on the road." I had the impression that she has seen many people through this part of the 'show'. I know that the surgery is necessary in order to remove the tumor—hopefully in total—and to send it to the lab for analysis. I pray that the results will be in my favor.

Wendy and I were pleasantly surprised with the atmosphere on the nursing unit. It really seemed to matter to the nurses if I was "feeling okay" or not. They certainly were a busy lot—but for the most part, kept a special smile for every patient. As Dr. Shaw entered my room, I looked at his face for any indication of the type of news he was about to deliver—I could not discern if it was "good news or bad news". I wished I had arranged with Wendy to be here at the same time—but that likely would have been difficult to predict.

"Well Joe, I think that we got it all out. . . but the lab report does indicate that some of the tumor was growing through the wall of the bowel. I would like you to see the specialists over at the Cancer Center—they will likely recommend some further treatment. . . as a precaution." What does this mean? Do they think it has spread already? Will I lose my hair? How soon can I see them?

It was another month before my appointment at the Cancer Center. I was surprised at how much rest I needed just to get over the operation. As each visitor came, it became a little easier to talk about what was happening—but they seemed to look so glum at times. At least the three grandchildren didn't ask me a lot of questions—they just wanted to play and read stories.

I felt as though I was waiting for another pronouncement as the doctor read over my chart—what would be the verdict? I wonder about the results of my blood test—I know that it is important. Without hesitation, the Dr. said, "We'd like to start you on six weeks of RT, and then follow that with a drug program for six months. For the RT you come here once a day; the chemo program is for one week of the month, for a duration of six months. The nurses will give you some more information before you leave. Any questions?"

The radiation treatments really weren't too bad—just meant that I had to arrange my other activities around whatever time I was scheduled to go to the Clinic. They did try to give me a time that I wanted as much as possible. In the last few weeks, I was very glad that Wendy was free to drive me—I felt as though I could almost fall asleep before I arrived back home. I did wonder how they could tell if those treatments were actually doing any good—it was so quick, over in a flash. Guess they are the experts. I wish some of the neighbors would keep some of their stories about people having chemo to themselves—it was bad enough that I had signed up. I don't need to hear any horror stories.

As the days rolled around for my sessions over at the Clinic, I noticed that I almost looked forward to getting there. The staff were all just great—they always seem to have a new joke to tell, they even remember to ask about the grandchildren, and they include Wendy in whatever is happening. In fact Wendy has started to go and have a coffee with one of the other wives, while I have my treatment.

ACKNOWLEDGING BODY SENSATIONS: KNOWING SOMETHING IS WRONG

When thinking about health, when and how do we determine that something is occurring that is 'not normal', or is 'out of the ordinary'? How do we attempt to make sense out of what is noticed? What are the consequences if we do not pay attention to the particular signs? Will the problem disappear? How is the decision to see the doctor made?

The study participants, most of whom were less than age 70, considered themselves to be 'healthy' individuals. None of them had any serious or longstanding medical conditions. Since the signs or symptoms being experienced were related to the process of elimination, there was a certain reluctance to talk about this topic with anyone. People were accustomed to this function being private. A wide range of changes and observations were identified, when in retrospect, each person shared his or her story.

Isabel talks of having had "*a sore aching rectum for about two to three weeks, and you know I just let it go for that long and all of a sudden I thought maybe there's something wrong. So what I did was when I went to the bathroom, I lifted one of the stools and sure enough there was blood in the crevices, you know like, that really scared me.*" Even the presence of blood

was not sufficient to cause every person to seek immediate medical care. Jim says: "*Through the years I had had piles which from time to time bled. So this symptom wasn't picked up by me quickly enough. I should have probably, when there was a bit of blood in my stool, gone and seen about it right away... but I didn't have the bleeding all the time. I was just too busy and not enough time...*" Several individuals spoke of "*getting really bad gas coming up, not having a regular bowel movement, noting alternating constipation and diarrhea, experiencing trouble having a BM, having diarrhea for a long time, or feeling as if one was not having a complete BM*". Catherine said, "*It got so that I was getting really preoccupied with what my bowels were doing. And this was going from, you know, it was something you did and you didn't think about it.*" In this group of people, the length of time of 'knowing something is wrong' ranged from a brief two to three weeks, to as long as approximately one year. For some, it was difficult, if not impossible, to determine precisely when their concerns had first developed.

Pain was another common symptom and was felt by about two-thirds of the participants. This pain was expressed as "*gas pains, sore aching rectum, started to hurt ... discomfort after eating, periodic pain in the bowel area, having terrible pain at the lower part of my stomach, having pain every day, or a sharp pain in my right side*". For Dolores, eventually her pain was also accompanied by vomiting every fifteen minutes. The degree of distress assigned to these sensations varied for each person. For some it was conveyed as a sense of '*mild discomfort, as that associated with*

constipation'; for others, the discomfort intensified until a point that it was now called a '*real pain*', in the general abdominal area.

Along with discomfort and pain, two people talked about being able to feel something in their abdomen. Mr. Edwards says "*I had a hard spot on the left side of my abdomen, and the (family) doctor did not identify it as being colon cancer or a tumor.*" Dolores said "*I have a swelling and it gets very painful…almost opposite of the naval.*"

Mr. Webber's experience was somewhat different. "*Summer wore on and one day just went to Fall and I was watching a football game in November and I had this sharp pain in my right side from early morning on. My wife kept saying are you going to come into work tomorrow or are you not going to. I said, Well, I don't think I will and then she said you better go down to the lab downtown. So I went to the lab and they took x-rays and they prodded and poked around and they said well we think it's your appendix. Which hospital would you like to go to? …He said if it's a simple appendix, there'll be a little scar there but if there is something else there, we'll have to work on that too so will you sign this consent form. I signed the form.*" The next morning, the doctor said, "*I've got good news and I've got bad news. The good news is we got your appendix out. The bad news is you have bowel cancer.*"

Only George said "*And when I did have a bowel movement, it was the shape of the stools that concerned me.*" However, it was not until George "*saw what I thought were drops of blood in the water as well*", that he took

action, stating, "*Well, I knew there had to be something wrong. I mean it, I said to my wife. There is something wrong. I said, this is just not natural, you know.*" For the five men in the study, all of whom were married, there was great significance to the sharing of this critical information with their spouse. It made the symptoms real—a pronouncement of something that had occurred. In several situations, the wives had not been aware that anything was amiss; in others, the wife already knew that her husband was '*not feeling well*'. Mr. and Mrs. Jones disagreed about how long the diarrhea had been a problem. Mr. Jones commented that the diarrhea had been present for about five weeks; Mrs. Jones remembered the time period as being more like a year. She said, "*I had to get pretty tough with him to get him to actually go to the doctor. In fact, I had to threaten to leave him*!" Mr. Jones was also the only person to comment about the marked weight loss, which occurred over an extended time period. Once a husband confided in his wife, she usually was the one to phone and make the appointment with the physician. The five women initiated their own appointments, and in some cases, did not have a spouse to whom they could confide their worries.

Three individuals mentioned noticing diminished energy: Mr. Jones said, "*That's what was bringing me downhill. I was just getting weaker and weaker. That was it, and more tired.*" Mr. Edwards, who had been experiencing various health problems for about a year, stated "*and then I was failing*". Mr. Webber, 57 years old, provided a comment that expresses an idea commonly held: "*I noticed last Spring, about a year ago now, that I was*

tiring easily and I didn't relate it to anything else but really getting older. I'd do simple things, like in the yard, and I'd feel really tired afterwards. I thought, Oh my, I guess this is what getting old is all about, so I didn't bother seeing a doctor because I don't like seeing doctors anyway." Seeming rather perplexed, Mr. Webber said, "*no blood... no change in size or color or anything*". It was as though he felt that his body should have given him some kind of warning, more than just fatigue.

Perhaps it was because people were talking about this part of their experience after time had elapsed or other events have assumed more importance, but it was noted that there were not many comments regarding the emotions surrounding these events. Mr. Edwards, who had three different health problems in the space of one year, spoke of "*Going back through the, the discomfort attached to it all and anxiety attached to it all, I'd say that the tumor is right at the top of the list.*" Jim stated, "*So when I did get around to be concerned about it I went to the doctor and had a full examination and to my utter surprise...whoo, this is really serious.*" Citing concerns about her husband's deteriorating health, Catherine 'put off' going to the doctor, saying "*You are the only one that I've told about having this bleeding in the summer time. I didn't even tell the doctors. I thought well, what the heck. I should have gone then, I know.*" In many cases, as the individuals relayed their experiences, they seemed eager to move along in the telling, and it was only as I noted their tone of voice, the pauses in speech, and facial expressions, that I could detect the dramatic impact that this unexpected situation had

created. Certainly, the usual routines were thrown off balance, and for each person, there was now the realization of the necessity to have their problem 'checked out'. As George said, "*Well I wasn't sure, but I, I knew there was something wrong. You know what I mean.*" What would the doctor say?

HOPING FOR THE BEST: SEEKING DIAGNOSIS

This part of the process – Seeking Diagnosis – is that phase from whatever point the person acknowledges to him or herself that 'something is wrong', up until the definitive pathology report is received from the physician. As the participants discussed their individual experience, one sensed that there was an underlying hope, with perhaps odds of 1:100 that the possibility might exist that this problem would not indicate cancer. Catherine had already diagnosed herself as '*I think it's a bleeding hemorrhoid. I didn't necessarily want to face it. That was what I was hoping for.*"

For the majority, acknowledging that '*something is wrong*', was quickly linked to a sense of urgency, to '*get on with it*', to find out what was wrong. The first action was to make an appointment with a physician. Isabel says: "*Right away I made an appointment with, my I don't remember who the doctor was, but anyway, I went to a doctor.*" This initial decision was greatly influenced by others being aware of the symptoms and acknowledging the seriousness. George commented, "*So I spoke to my wife, and my wife said, set me up with an appointment to see the doctor (family practitioner)…So then he set me up an appointment with the specialist right away. From the time that I was diagnosed with it 'til the time of surgery, well I bet you it wasn't*

even a week. Dr. Price had me in there just as fast as anything." Even with Mr. and Mrs. Jones, once they agreed that the diarrhea was '*not normal*', the scenario presented as "*And we finally decided, then the wife chased me to the doctor.*" Jim spoke of "*I went at 4:30 in the afternoon one day, you know, not wanting to take any time out of the business day and ... this was on a Friday, and he asked me to be prepared to go to the hospital for further tests Monday morning ... felt turmoil. Upset and everything else... going back to it now, it seems sort of like a blur but at the time it was pretty upsetting.*" Catherine's experience was similar "*Like as soon as I described my symptoms we got on with it...*"

The comments that portrayed this sense of urgency were associated with nonverbal cues, which conveyed some of the recalled emotions. Certain words were given verbal emphasis (for example, right away or was pretty upsetting). Pauses occurred in their delivery, or tears appeared in their eyes, demonstrating evidence of their remembered worry.

There are many different ways of being diagnosed, but a common denominator was a variety of tests and procedures that are ordered by the doctor. For Jim, who said "*I had a full examination (meaning that it included the DRE—digital rectal examination) and to my utter amazement and surprise and dismay he said, 'You've got cancer,*" there was the suddenness of receiving this declaration.

Arrangements were made very quickly for Isabel and for Catherine to have a sigmoidoscopy exam. As Isabel said, "*Sigmoidoscopy, right, and*

yeah, that's when we discovered that I had a little tumor right. I think it was ten centimeters up the rectum. And, I think it was a week later they did the colonoscopy... and they found polyps. They took them off. When I saw Dr. Ball, he told me that I have cancer." George talked of "*they tried to see what was all up in there. They spotted a blockage right away. Then Dr. Price did a scope. I could see what they were looking at on the monitor... he geared right in on, on the sore, the tumor itself. And he said 'that is your problem George'.* Catherine talked of having two sigmoidoscopies in one day "*went on to break the Guinness book of records for the most sigmoids in one day... He didn't say I think it's cancer or whatever but by this time I, I already knew.*" Both Mr. Webber and Mr. Jones had their colon cancer discovered in the course of being treated for another medical problem—for Mr. Webber, it was the suspected inflamed appendix; for Mr. Jones, it was during the investigation for a problem with his left kidney.

The knowledge of anatomy, as well as the familiarity with an extensive variety of diagnostic testing terminology was quite evident in this group of people. Words such as "*sigmoidoscopy, colonoscopy, barium enema, ultrasound, CT scan, MRI, polyps removed, took a sample*" were heard frequently as each one described the necessary examinations. One senses that these terms have been recently learned given this new situation.

It was not uncommon for the physician to make comments such as said to George, "*He figured with my age, given what I was telling him about, what I was seeing, that it could be cancer... but he wasn't sure. I didn't like to*

hear that." Although for one younger person, "*I think that's why they had trouble diagnosing it because of my age*." Mr. Edwards received the following: "*He said that the firm area of the bowel on the left side was more than likely a tumor and it was probably cancerous. I then had a colonoscopy done, a biopsy was taken and the biopsy identified cancer.*" In these situations, it would seem evident that the physician was trying to prepare the person for the potential or the inevitability of 'bad news'. Even though possible bad news was expected, one hoped for the best.

WONDERING ABOUT THE FUTURE: RECEIVING THE DIAGNOSIS

Whether the final medical diagnosis was based primarily on clinical observations and experience, or on the more formal pathology report, there was a remarkably creative range of words used to provide the definitive pronouncement. The following list, derived only from these ten participants, gives some sense of how 'cancer' is still not a word that one wants to use. These words and phrases include: "*obstruction, a little tumor, growth, spots, it, polyps, blockage, thickening, mass, collection of cells, sample, the sore, biopsy, a piece, something there*". It was noted that these more euphemistic words were often, although not always, used within the same segment of conversation, as the actual term '*cancer*'. When physicians spoke only of the '*cancer*' participants recalled them as being very direct, as in "*Dr. Ball came into the room where I was and told me that I have cancer*" (Isabel); even before surgery, George heard "*Taking everything into consideration, he would*

in all probability say that it was probably cancer". Mr. Jones said, "*They also picked up that I had cancer of the colon from the other tests*".

Receiving the diagnosis of 'cancer' for Mr. Edwards and Sharon differed from the other participants in that they both experienced an investigative phase that was longer, less clearly delineated, and more fraught with uncertainty. As Sharon has mentioned before, in part, due to her younger age, and also, a more unusual set of physical problems, "*Dr.—they didn't diagnose it right away. They kept giving me, something to get me, you know, going. Nothing was happening, so finally the doctor sent me to the specialist. Had me in hospital for a couple of days, then called in Dr. Ball.*" Mr. Edwards talked at length about the three different health concerns that he developed over a one-year time period. Following surgery for an enlarged prostate, he continued to have abdominal pains. He did eventually have a colonoscopy, and was diagnosed with '*irritated bowel syndrome*', with a recommendation for '*follow up by the GP*', "*which he (the doctor) did not do*". Eventually Mr. Edwards noticed "*a hard spot on the left side of my abdomen*", changed doctors, had a barium enema, colonoscopy, and "*a biopsy was taken and the biopsy identified cancer.*" Mr. Jones said, "*...just the word is enough. Well, yeah, it's kind of scary because you, you figure, well you're not going to be around that long. You figure your time is short.*"

For others, the conclusive announcement was given following an operative procedure which was, initially, more exploratory in nature. That is, the surgeons were not as certain, or were unsuspecting, that the presenting

symptoms were due to the presence of a malignant tumor. It was only following the operation, that the doctor could say definitely that the problems had been due to, in most cases, intestinal obstruction. "*I was having terrible pain, causing me to be vomiting every fifteen minutes, my husband called the ambulance. They wanted to keep me but I wanted to come home. I wanted to talk it over with my own doctor. The next day, he said get back to the hospital. I don't remember going back to the hospital. Then this other doctor did the surgery. I was really sick, I was 'out of it' for almost a month*", relates Dolores. Linda underwent surgery in September, for what seems to have been a separate health problem, continued to develop more gastrointestinal symptoms, and finally, in the following April, was taken to surgery once again: "*He put me in the hospital in the morning and he operated late, late that night. And, he could not take the tumor out. It was very low in the rectum. So what he did give me was an ileostomy...*"

How do people react when receiving the diagnosis of '*cancer*'? Mr. Webber said: "*Well, actually cancer, it, the word frightens everybody you know, so you think of, you know, are your days numbered, and this sort of thing and you, you're glad you did the things you did... like look after life insurance and investments so that your wife will be looked after. That's about all that went through my mind aside from the fact that I hope that I can get over it.*" Isabel recalls: "*Dr. Ball came into the room where I was and told me that I have cancer. And I always wondered how I would feel if somebody would ever tell me, you know, you've got cancer. Boy, I sure found out that*

day… It was devastating, So I said to him, well, what do I do now, cry? He said, 'go ahead.' Anyway, I cried that day... and that was it." Dolores, who underwent surgery for a bowel obstruction, was subsequently told that "*at the back of my stomach was this cancer*". Catherine, after making a conscious decision that she was '*safe to drive home*', talked of "*So anyway, I got home, walked in the door and said 'Sorry, I'm late. I have cancer and I have to have some surgery and, sorry I kept you waiting.' Poor old John and I burst into tears.*" Catherine went on to say, "*And it, you know what, getting cancer, it's like you join the club you didn't want to join.*"

It was evident as each person talked about their recollections of that moment when they were told that "*yes, you have cancer*", that both the physical environment and their emotions at the time were highlighted. Mr. Webber said: "*I was just sort of coming out of it. Well, I suspected something cause there was a nurse on my left hand and a lab tech on the right. And I thought I'm here for an appendix. I wonder what is going on here, and the lab tech said, you know I've never taken this test before. And the nurse said, very quietly, it's for bowels or something. And I thought right then, you know this is a lot of work for some guy with appendicitis. And I sort of started thinking something was wrong. Maybe they do that sort of thing intentionally so the shock is not so great when they... was just before the doctor came in.*" Catherine experienced the surgeon, being "*the kind of doctor that thinks out loud*", announcing "*Yeah, it's cancer*" as she was in the undignified sigmoid exam position. He went on to say, "*We won't do a biopsy, there isn't anything*

more that we need to do.", and I rolled over and pulled up my clothes. "And the other thing is that office was so damn cold I thought I would die!"

Acknowledgement of the irrefutable nature of the diagnosis included the extent of the investigative tests, and the fact that more than one physician was of the same opinion. As Jim said, "*The tests that took place were very, you know, exacting and then they sent me to another hospital for the ultrasound and other tests, and I went though those and it just confirmed the tumor and the size of it and all this sort of thing. I forgot to mention that the doctor I was sent to by my GP, was a person who has done a lot of research in the cancer area and along with another two doctors…so I felt very fortunate.*" In most instances, the minimum number of physicians involved in the diagnostic phase was two: the family doctor, and the surgeon to whom the patient was referred.

One can only try to imagine the whirl of thoughts and feelings that go through the mind, as each person hears the definitive pronouncement from the physician. For several participants, as the investigative phase progressed, and the pieces of the diagnostic puzzle came together, statements of "*provisional diagnosis", "strong suspicion", "in all likelihood", "chances are*" were made, and led, then, to the initiation of the surgery. Even though these individuals were somewhat more prepared for the outcome, there was still the sense of ominous expectation as the doctor began to speak. Isabel recalls: "*Dr. Ball came to see me and said, 'We've got it all!" and that was three years ago now.*" George says: " *I might have still been a bit woosy, probably the day*

after, he told me that everything went just fine, he was telling that he got everything, you know, that he was quite confident that he had it all." For example, Jim had been given prior information about the staging terminology for bowel tumors, so was relieved to hear the surgeon say, "*The tumor has been examined, and it was not through the wall, and it is a type 'C'*. He had an idea that this was *"good news*".

Each person acknowledged that from the moment of receiving the '*cancer*' diagnosis, his or her life changed. The focus now was on 'dealing with the cancer'; learning to live with a diagnosis of bowel cancer. As this announcement was given, it was not unusual for the physician to immediately begin to talk about the other possibilities for treatment of the malignancy.

WHAT AM I GOING TO DO?: MAKING DECISIONS / PLANNING TREATMENT

The verbal pronouncement of 'cancer' was followed with the physician outlining subsequent avenues for treatment. For all but one participant, the initial therapeutic approach was surgery. In most instances, the time from pronouncement of the diagnosis of cancer until the date of operation was quite short, that is, in the range of about one-week. As George recalled, "The doctor said '*the sooner the better*'." When Jim met with the surgeon, "*he recommended surgery right away. He said 'let's get at it real quick'. I saw him on Friday, and was in the hospital on Sunday.*" For Catherine, the plan for surgery was complicated by two factors: she learned of her diagnosis just before a trip to visit family for Christmas, and she needed to make arrangements for the care of her spouse. Her doctor said, "*I am really sorry to*

have to tell you this, at this time, but we can get something done right away, like before Christmas." She said, *"No, we're not doing this before Christmas".* As these people spoke of their experience, remembering the relatively short waiting period before the surgery, once again, the 'sense of urgency' so often connected with the cancer diagnosis was invoked. Catherine had a different viewpoint however, saying, "*I knew that if two weeks made that much difference, it was too late anyway*." There were two situations where the date of surgery was later. Mr. Jones understood that it would be better for him to have his operation when both surgeons were available, so waited for the one to return from a one-week holiday. Mr. Edwards talked of a very frustrating two months while waiting to receive a date for surgery. As he said, "*The layman is not familiar with the procedures in the hospital to take care of operations…let's get this thing going…let's not diddle around. It's my life that I'm talking about, and that is the most important thing. It was a case of losing my life*!" He was still so angry that he asked me to turn the tape off temporarily at this point.

The possibility of creating a colostomy as part of the surgical procedure was addressed by the surgeon. Understanding whether the colostomy would be temporary or permanent had a significant impact on three individuals, and influenced, in part, their exploration of alternatives. Sharon remembers going to several physicians, and being so relieved when she linked with Dr. Ball, *"who was excellent and solved the problem."* Jim recalls the surgeon telling him "*because the tumor was so low, it would be very*

difficult to save the sphincter possibly. He didn't know how extensive the surgery was going to be." He had "*asked right away if the colostomy would be temporary, and he said 'no'. The choices were, get it done, or you know, you could be finished, sort of thing.*" Even though Jim indicated great trust in his primary surgeon, nonetheless, he asked for a consultation with a second specialist. "*I had also gone to Dr. Todd and asked him what he felt about the surgery, to get a second opinion, before I went in, because I felt that I should do that.*"

Through the telling of what had occurred for each person regarding the initial surgical treatment phase, there were frequent comments about the explanations that had been provided. "*He had given me some material to read, and it was pretty explicit about, whether it was an A,B, C, D type of tumor, whether it was through the wall or not through the wall,*" stated Jim. Catherine attended a special pre-operative teaching session, "*I must say I was really impressed with the approach to pre-op teaching. She was really clear on what was to happen. I had handouts of about everything. I had an opportunity to ask questions. They went over so many things. I guess I must have had questions too.*" "*I was well informed about things like that, and Dr. Ball of course, told me about the surgery that he might have to, you know, it all depends, he might have to give me a colostomy*", said Isabel.

For eight individuals, the first treatment was the surgical removal of the tumor. As with any operative procedure, it was important for the person to have a clear understanding of what would be entailed. Catherine's situation

was typical: "*He was really keeping me informed. He was seeking informed consent. He said, you may need chemotherapy, but we won't know until we do the surgery. It won't be the kind of chemotherapy that makes you lose all your hair, you won't feel that sick.*" Jim and Catherine, who only required surgery to remove the tumor, were spared the task of deciding whether or not to participate in adjuvant treatments. "*I came along very fast and the good news, after having the tumor examined, was that it was not through the wall. He was very confident that I would recover fully and that I would not need any chemo or radiation,*" relayed Jim. Mr. Webber also understood that whether or not further treatment was recommended, would depend on the pathology reports received, "*He had this information come back, he had it all written down, and he said, 'Well, it's not as bad as we thought initially.*"

Most of the information on which decisions about treatment were based was supplied verbally by the various physicians. Several people indicated their faith in the doctor '*to do the right thing*'. There was a definite sense that the physicians were the experts in this area; that they knew what to recommend. Mr. Jones related, "*The doctor says 'which one do you prefer'? I said 'it's up to you, you're the doctor, not me.*" Mr. Webber's comment was: "*My approach was to do just what the doctors said and hope for the best.*" Mr. Edwards spoke of being '*invited to make inquiries if you have questions*". Isabel relied on the specialists to tell her when it was necessary to stop chemotherapy treatments. "*Dr. Smith thought it was terrible, but I couldn't take the last three. He said 'that's too bad, but we're not*

going to do it, because we might have to cut off your toes, if you got gangrene or whatever'."

Only one person adamantly refused further treatment, following the initial surgery. Dolores said, "*He asked me to go to the cancer clinic, and I said, I don't want any treatment or any medication or anything like this...and that was at least four years ago.*" She continued, "*I've seen people. One time in Montreal and this poor old soul...every time they'd take her down for treatment, oh, she would be so deathly sick...it must have been chemo...I don't want nothing.*" The remaining seven faced key decision points when presented with the options related to chemotherapy and radiotherapy; and for two, when the cancer recurred. On the whole they all relied on the doctor to do the best for them.

Follow-up chemotherapy was recommended for seven of the group. Each person made comments that conveyed their understanding of how the decision was reached to recommend chemotherapy. "*Maybe three or four days later, he came in and had a chat with me, and told me something about the lymph nodes. He took them out, and he was quite confident that he had them all, but he said to be on the safe side, I would advise you to take chemotherapy for a year,*" said George. One specialist had gone on to explain, "*...lymph nodes are like a streetcar, they travel here, there, all over. You can never be certain.*" "*I was scared, I, what I mean, chemotherapy, pheww...I'd heard so much about chemotherapy, you know how it makes you sick, and your hair falling out. I went into a room with other people that are*

being briefed by the nurse, about all the things that can happen, just trying to prepare you." Mr. Edwards said, "*There are a large number of chemicals that they can use, and in different combinations for the different types of illnesses. I mean breast cancer is treated differently than colon cancer....But, as a layman, your view of this sort of thing is that it looks like throwing darts on the wall. They give you some of this stuff and they give you some of that stuff.*" As Isabel recalled, "*The doctor told me that the chemo was for the cells, cancer cells in the blood. . . I was well informed about things like that.*"

The manner in which information about the adjuvant therapies was provided elicited commentary from several participants. Isabel, Jim, and Mr. Jones all mentioned that they had "*received lots of pamphlets*", as well as the "*explanation they give us up there. They were pretty well on target.*" (Mr. Jones). Prior to his surgery, Mr. Edwards contacted the Cancer Society: "*Over the phone they read one of their pamphlets on colon tumors, what is usually done and why.*" In addition, he recalled, "*In all of the papers they give you prior to any treatments they, they try to give you an insight as to what's coming up. And you are invited to make inquiries if you have questions.*" Most people talked of receiving their information on a one to one basis with either their surgeon, or a nurse at the Cancer Center, or in a group setting. Some had been surveyed as to which approach they preferred. As Mr. Edwards said, "*I think I much preferred the one on one, but I know it takes more time. In the group meeting, you still gained enough information because everybody in the meeting, each one had a different problem.*" Linda remembered, "*It's*

only two months after surgery, and my mind is still foggy. They tell you all these different things, and you read all these brochures, and you don't take it all in." Mr. Webber recalled, "*They sort of prepare you for the worst; and then you sort of hope for the best.*" As the person having had surgery most recently, Catherine spoke of "*pulling a bunch of stuff off the Internet, a really good web site, I think it was the National Cancer Institute information*". The provision of both oral and written sources of information was important to each person.

It was evident that each person became increasingly more knowledgeable about their own anatomy, and the disease of cancer. The adoption of more medical terminology occurred over time as a person was exposed to the possibility of different aspects of treatment. As Mr. Edwards commented, "*The whole science of oncology is kind of strange to the layman*". Understanding the relationship of the results of the pathology examination to the determination of treatment modalities was noted. Again, Mr. Edwards stated, "*The pathology report had already come back at that time. They said I had one lymph node out of 20, and I don't know how many tests they do, but that was pretty good, one twentieth.*"

Throughout these early phases of the cancer experience, the role of the spouse was remarkable for six individuals. It was as though they were inseparable; this was a shared event. Sharon commented, "*They explained things very well. Ralph was with me at the time and whatever I missed, he picked up on.*" In speaking of a teaching session, George said, "*All the things*

that can happen, just kind of trying to prepare you, you know, for it. After listening for about an hour or so, my wife was there with me of course, I went down at 11 o'clock and had my first chemo injection." "*I had a lot of good backing from the wife too. She kept me going. She kept bugging and pushing and it helps quite a bit, I'll tell you.*" related Mr. Jones. Jim remembers, "*So things were moving very fast. For Lynn and I it was quite a tough time.*"

For those who did not have a spouse to share this experience the decisions made were theirs alone. For others, it was evident that the spouse played an important role. Sharon said, *"Well, each time, of course, Ralph and I would talk it over and make a decision.*" Mr. Jones, who adopted a more passive stance, relied on his wife, "*The wife would do the asking of the questions. And then she tells me.*"

Through this phase of the cancer treatment experience, there was an intense and pervasive sense of urgency connected with the making of decisions. This was especially noticeable regarding the recommendation for surgery. Jim commented "*...you know, the choices were, get it done, or you could be finished, sort of thing...It was a rush. Dr. Good made it very clear to me that we don't have a lot of time to fool with this.*" Confirmation came from another surgeon, when Dr. Todd provided a second opinion, "*He thought it was expedient to go and have the surgery done right away.* "Mr. Jones said, "*You don't really have much time to think about it. You've just got to get to it, and that was it. You have to get it over with.*" Linda remembered, "*I had no time to think about it. I had no time to think about the horrors of it.*" Most of the

study group was very deliberate about the action to hand over key aspects of this process of 'deciding' to the doctor. It was as though this was a reasoned, conscious decision made by the individual, telling themselves: "I am putting my trust in the hands of the medical experts."

Some individuals chose to be more involved in the organizing of the treatment plans. Catherine decided that she needed time to enjoy a family Christmas, and to make care arrangements for her spouse, prior to surgery. She said, "*I believe that it's good for patients to take control so that they're the ones in the driver's seat. I don't think that you should give up your life that way.*" Linda illustrated another strategy for taking charge of her own health situation by, "*I think it was the second day when I was in hospital. I had a list of questions by this time...and he told my husband, 'I just love people with lists'. Otherwise I would never remember everything that I wanted to ask the doctor.*"

GETTING THROUGH IT: BEING TREATED

There are three primary methods used to treat cancer: surgery, chemotherapy, and radiotherapy. Once the pronouncement of "*Yes, you do have cancer*" is made, there is almost simultaneous presentation of the usual and potential treatment options. The individual proceeds through the phases of Planning Treatment and Making Decisions relatively quickly. At this point, there is a determination to 'get through' this aspect of the experience. People are most accustomed to the surgical approach, 'to cut out' the cancer. The details related to the administration of chemotherapy and/or radiotherapy are

not so familiar. With this group of participants, all underwent surgery; two accepted the advice to take adjuvant chemotherapy; and five received both chemotherapy and radiotherapy. One person declined additional treatment following the initial surgery; two people did not require treatment beyond surgery.

As each person talked of the treatment that they had received for their colon cancer, whether their experience was within recent weeks or several years prior, the memory of specific details was extraordinary. Three years later, George stated, "*I was in the hospital for ten days, alright, got out of the hospital April 30. I had the month of May, then started chemotherapy June 01.*" In talking about his time in hospital for surgery, Jim said, "*So, in a matter of seven days after my surgery, on the eighth day I was released, so this was October.*" Linda recalled, "*I had surgery in September to remove what they thought was a cyst on my right ovary. In December, I was still having problems...we were away for the winter...then on April 24, four months…an hour and one half later I was at the specialist. So April 25 he operated late, late that night.*" In addition to recollections of dates of events, it was common for individuals to know the size and location of the tumor, precisely the number of radiotherapy treatments they had received, what time they had gone for treatment and arrived home, and how many lymph nodes (if any) were involved. Mr. Edwards noted "*the operation lasted another hour longer than what Dr. Ball had thought it would take. The tumor had grown not only around the colon but had gone away from there and was all along the kidney*

and along the back of the body cavity and it was huge." One sensed that he was very accurate in his description.

Surgery. For several people, the surgical procedure for removal of the tumor, was their first encounter of this type of procedure. "*The surgery went well, and of course, that was quite an experience. I have never had any kind of major surgery before. We used the pump system for pain and that worked out well,*" said Jim. George, also in his early 50's, spoke of "*...to face the fact that I for the first time in my life was going to undergo some major surgery. I was always hoping that I could get through life without ever having to be cut open.*"

Catherine said, "*One of the things I feared is the general anesthetic. I've had it where I've been totally zonked for two or three days, and felt so out of control. I was really concerned about the anesthetic. I wanted the Dom Perignon of anesthetic.*" From Mr. Edwards' comments about his recovery at home, "*I was getting sore and I couldn't go out and walk at all because my incision hurt so much. To make a long story short, it was healing from the outside and draining a cavity inside where the fluids were developing and flowing out.*" He developed a postoperative wound infection, and subsequently required Home Care support.

Surgery could involve the formation of a colostomy. Receiving one or not receiving one, was seen as another form of 'pronouncement'. Mr. Jones said, "*I was terrified that I was going to wind up with the bag, which I didn't want. In the recovery room, I wouldn't come to. They finally called my wife*

and she came to the hospital. I would almost come out of it, and then I'd go back into a daze again. She saw me feeling (my abdomen), and she said, 'No Mike, there is no bag. ...So I guess I came right out of it." His doctor had explained that there was a possibility for a colostomy. As Mr. Jones continued, "*they couldn't tell you ahead of time...they were pretty sure I was going to have it.*" For Linda and Sharon, the temporary nature of their ostomies, meant that after a few months, they were 'reconnected'. In a positive tone, Linda said, "*It's really incredible what they can do now. It's better than being dead.*" In talking about caring for her ostomy at home, Linda recalled, "*The hardest thing was cutting the hole the right size, and I was upset and crying (laughing now). And because you have to bend down all this time, your neck's so sore, you can hardly do anything.*" Sharon's experience seemed a bit different, "*I got used to it. It was kind of like brushing your teeth, you know, It was just part of the health routine that you have to do.*" Jim's surgical excision of the tumor, resulted in the formation of a permanent colostomy. Recalling his experience, Jim said, "*The next thing I know the surgery's over. I was up and about right away of course. The good news was that I would not need any chemo or radiation. I was somewhat prepared and yet, you are never prepared because I don't even know what chemo and radiation would mean to me.*" Jim knew that he was one of the fortunate who only needed the surgery.

Chemotherapy. A second line of treatment for seven people was the addition of chemotherapy. Mr. Jones noted, "*I took the chemo for three*

different times...on a week, then off a week, and on a week and off a week, and that repeated again." Similarly, Mr. Edwards said, "*I went through several sessions of a week of chemotherapy and then two weeks off, took a week of chemo and a couple weeks off. You go into the hospital and you stay there six hours and they use a pump, which you carry around in a little bag. They pump this chemical into you over the six hours, would start around 8 or 9 in the morning*". "*They set up this six months of appointments for one week every month. I went the first few times, and you know, you just do it,*" recalled Mr. Webber. Linda remembered, "*They start your chemo needle in your arm, they give up a little bag, so that you can walk around and be more free. It was a tough week. All of a sudden you're branded. I felt that everyone was staring at me.*" The process of initiating the intravenous brought comment from Mr. Edwards, "*When a person gets older your veins become less receptive to a needle and so the nurses have trouble getting that intravenous needle into your hand or your arm. I think when they try about three times, then they give up and someone else takes over and tries. But, none of this is nice for the patient, but it's one of these things that just happen. And you can't get away from it.*"

The side effects of chemotherapy were a major subject for those who received this form of treatment. Several spoke of experiencing nausea of varying degrees. Isabel said, "*I would feel terrible and queasy, but I never did vomit, you know, every time I'd get close to the Center to take the chemo, I'd get that sick feeling. I kind of hid it.*" Mr. Edwards related, "*You also get*

nauseous at the very beginning. Then they give you an antinausea drug, to try to control that. I only saw one person get sick [vomit] in chemotherapy." Mr. Crawford had a similar comment, "*I had the needle and also the pills. Those made me feel rotten, but not to the point where I was sick. I never got sick. Just made me feel nauseated. I could not even stand the smell of the tap water.*" Loss of appetite was common for everyone, as was fatigue. Mr. Crawford said, "*I would just lie around on the couch. I just didn't have the 'get up and go' when I was on those things. I just didn't want to do anything.*" In order to illustrate this point, Mr. Webber said, "*I'd get up in the morning and I'd shave and brush my teeth and have to sit down and rest. Then I'd comb my hair and I'd sit down and rest; I'd make something to eat, eat that, and rest again. It was just awful.*" Each participant seemed to have the personal goal and determination to 'get through' the necessary treatment, in spite of experiencing distressing side effects.

Isabel was unique in experiencing two other problems. "*My mouth was so sore, the inside of my mouth, my gums. My dentures made it so painful.*" Eventually it became necessary to terminate her chemotherapy treatments, "*My circulation was poor, and I was having an infection in the toes. So the doctor said that we should not do that anymore because I could lose my toes.*" There was the sound of resignation in her voice as she spoke, a wondering about the impact of not receiving the last few chemotherapy sessions.

Chemotherapy and Radiotherapy. Five individuals were on a treatment plan which included both chemotherapy and radiation therapy. An understanding of the process of administering radiotherapy was conveyed by Mr. Edwards, "*Since the tumor was lying along the blood vessels to my left leg, the doctors left two titanium targets inside, in order to show where to concentrate the radiation later on. They then can map out on you where they are going.*" He also spoke of, "*They mark your body...we had specific instructions on how to handle things so you don't lose these marks, for the week of treatment.*" Others were more like Isabel who said, "*All I know is that with my colon cancer and the men with prostate, we went to the same machine, but the women with cancer of the breast went into another room. I imagine to a different kind of machine.*" Sharon, like many, spoke of the radiation treatments, "*I'm not sure how much radiation I had, but it was a minute on one angle, and a minute on the other angle—lasted for something like six weeks.*"

For these people, fatigue was the outstanding effect. As if to relay the intensity of this remembered sensation, people often slowed their speech, speaking very deliberately, measuring each word. As Mr. Edwards said, "*You spend a lot of time sleeping, that's what you do. You try to get rested at night, but you wake up the next day, and you have this, it's a chronic fatigue. You do a few things, and then you go rest again...With my routine, it took a week to a week and a half to start feeling normal again.*" Similarly for Mr. Jones, "*When you came home, you were dead beat. I would just have to rest more. .*

. two hours in the afternoon. Most of the time I was exceedingly tired." Sharon commented, "*It seemed like heavy radiation. I got really tired...When the end of the treatment came, that day, I kind of hit a brick wall. I was in bed for three days. I just couldn't get out of bed.*" Linda talked of, "*It just made me rest. I spent a lot of time just laying down reading. You're so tired through this time, towards the end you get tireder and tireder. I would lie down to watch TV and I would put it on mute for the first commercial, and wake up 50 minutes later.*" She laughed as she said this, but there was a feeling also, that she had 'lost' this time.

In addition to the fatigue, distressing lower gastrointestinal symptoms were common. Mr. Edwards spoke, "*I think that all through that treatment you have gastrointestinal problems. I would have an awful lot of gas and there would be a lot of diarrhea. They would recommend you use Imodium to try to control that, but you're just always having problems with the digestion and the proper functioning of the bowel. I mean the bowel just goes through Hell there for awhile.*" He went on to describe the discomfort that he felt, "*You're always going to the bathroom, and you end up burning the skin all around the anus. . . so you have to take these little sitz baths or soak in the bathtub. We called it 'the ring of fire'.*" Linda also experienced extreme skin irritation related to radiotherapy. "*It started getting worse and worse and they gave me a cream that I could use, but it didn't help. It was pretty red and sore and it was fiery red. I tell you, it's no wonder babies cry when they get diaper rash. This was a*

killer...I was literally raw down there. That really was the worst symptom of all."

Most individuals were pleasantly surprised that the loss of hair was minimal with their type of chemotherapy or radiotherapy. Mr. Jones expressed, "*I never lost any hair. A friend of mine lost all his hair, completely.*" Mr. Webber briefly mentioned, "*My hair is getting a bit thin, but it was getting thin anyway.*" Isabel did experience a much greater amount of hair loss, "*I was losing my hair, all of my hair. It was devastating...but it came back curly, but only for three months, and then the curl disappeared.*" Isabel also joked about the loss of pubic hair. When one of the nurses forewarned her, she said, "*That's okay—nobody ever looks down there anyway.*"

In spite of the unpleasant effects of chemotherapy or radiotherapy treatment, those who received either one or both therapies, conveyed a general sense of optimism. Mr. Crawford said, "*I never came out of there depressed at any one point.*" Several people gave the impression of camaraderie among those undergoing chemotherapy particularly. Perhaps it was somewhat like a social gathering, as they all took their positions in the recliner chairs of the outpatient department. Mr. Jones recalled, "*When I was taking the chemo, there were at least 35 of us to go through there everyday.*" Mr. Crawford continued, "*The fear went...I'd just be sitting there, on some Thursdays and there would just be people my age. We'd chat back and forth. It never bothered me.*" Mr. Webber also noted, "*What surprised me was how many young people were there going through chemotherapy...most of them*

were younger than I was." Mr. Jones remembered how the Clinic environment was as positive as possible, "*They had just about everything there, but I never used them. They'd have the warm blankets right in the machine, and they had fountain water if anybody wanted it. And they had juices and then, that outfit came through with coffee and biscuits every morning.*" Even the ability to have input into the schedule for treatments was noted, "*They will arrange almost any time of day. I think that people come in from 7:30 in the morning until 9:00 at night or something.*" (Mr. Webber) Mr. Crawford said, "*I didn't even mind going on a Thursday, although the time of day sometimes wasn't all that convenient, but I got used to that.*" When people were only receiving chemotherapy, as for Mr. Jones, "*For the first three weeks, it was four day sessions, and you were there about two and a half hours. But then, when they added the radiation, you went in at 8:00 AM and you didn't get home until 3:00 in the afternoon...you felt a little rough when you finished that.*"

The ability to maintain one's usual activities was viewed as a significant factor. Mr. Crawford proudly said, "Still, I even went golfing when I was taking those pills. I wasn't going to let it beat me, you know. I maybe laid around on the couch more of an evening, but not during the day. I would say that I was about 75% of my normal self." Mr. Jones talked of, "Even though I went for a nap almost everyday, I was still out shoveling snow—for us and the neighbors too." As one of the younger individuals, Mr. Webber was concerned that he was able to continue working at his business, particularly since his treatments were occurring during the busy pre-Christmas season. Jim spoke

of "going back to work, at about the fifth week" following his surgery. Returning to work served as a form of announcement to the rest of the world: "I am going to get through this thing. I am going to do what I want to do. . . what I usually do." He knew he would have to wait and see what was to be his future.

WONDERING WHAT'S AHEAD: WAITING AND MONITORING

Between the time of first recognizing the need for diagnostic tests because 'something is wrong' and a time, months or years later, when, for some, there is difficulty even in recalling when the diagnosis of bowel cancer was received, there occurs a multitude of events, and milestones along the way. What are these events? How do they link with the experiences for each person? How do these events contribute to a person's understanding? Even though the person diagnosed with bowel cancer is striving to live life as normally as possible, there exists a sense of 'watchful anticipation', where one must be vigilant to any signs out of the ordinary. Life is one of waiting and monitoring.

Waiting to receive the pronouncement based on the pathology report following surgery was a most difficult time for each person. While many were given this information within the first few days following surgery, Catherine, whose surgery was more recent, talked of, "*I guess I was discharged before they had results. And they said that wasn't unusual. The doctor was to be in touch with me. But then I had complications and went back in and I still didn't know. At this point I was getting concerned. Finally, they checked with*

somebody, and the head nurse came in and drew the curtain around and she wrote down for me what stage it was." Catherine knew that the recommendations about the need for further treatment would be based on the results of the pathology analysis. This was a critical time.

For all except one person, surgery was the initial treatment to 'deal with' the cancer. Isabel, who received radiotherapy and chemotherapy prior to surgery, remembered, "*You know something, mine [the tumor] was shrunk so small they could hardly find it.*" Even knowing this did not eliminate her concern about the possibility of having an 'ostomy', "*The first thing when I came out of surgery, I felt to see if I had that bag there. It wasn't on.*" The three individuals who required an 'ostomy' identified particular points by which they could gauge their progress post-operatively. It was Sharon who said, "*I noticed it [stoma opening] got smaller and so sometimes, for awhile I'd find that if I was putting the same thing on it, and it was getting smaller, so I wasn't dressing it right. But I caught onto that.*" Jim recalled, "*I was told at the time, by the ET nurse, that my stoma probably would be smaller over time, or would change in its appearance. And mine to this point has not...which means it must have been sewn in very good. That's a positive because I do know that there can be some problems with the stoma, especially if it inverts itself.*" Linda, who received an ileostomy said, "*All I ever seemed to be doing was changing this bag. When I checked with the nurses, they would ask me how often I was having to dump it, and I got the impression that it was more often than I should have been doing it. But after a few months, things settled down,*

and my system went back to normal and started regulating itself." About five months later, discussing her progress, Linda stated, "*By that time, I was coping with it. I could almost forget about it. Like sometimes, for awhile there, that's all you thought about.*" Those who had an ostomy were particularly aware of any related changes. Mr. Webber's cousin, a doctor in England, immediately asked him if he had a colostomy. He replied, "*No, and I assumed that if it's lower down, it's more serious.*"

The schedule of appointments for the 'checkups' at the Cancer Center is organized to occur more frequently during the first year following diagnosis, and then to be required less often as time progresses. Sharon initially thought the surgery would be the only treatment required. As she described, "*Well, in the beginning, I thought the cancer was gone. And I was really upset when I found out that this was going to be the sort of thing I had to check all the time. And yeah, I didn't like going but...*" Isabel talked of having a *'good feeling'* regarding her visit to the Clinic, as "*I'm going to know one way or the other if I'm still okay...hurry up, I want to know now.*" As Mr. Edwards said, "*I went to see him every three months for a checkup. For two years, I saw him every three months, and now we are on a six month cycle.*" Similarly, Jim talked of "*After a year or so of every two months, then every three months, until the second year, and now I'm at the every six months level. Then I go to an annual checkup here not too far down the road.*" Mr. Jones was "*still on the every three month, but they're stretching it a little bit more now—will be four months this time.*" Catherine's experience was, "*After I had my first visit at the*

Cancer Clinic, then the nice part is he said you don't have to come here again. You can see Dr. Todd in his office. You will go every six months for the next five years." People came to understand that this plan for the follow-up appointments was part of a normal routine, and that gradually, the time between visits would be extended, providing no problems were evident. Dolores' circumstances were different, "*He changed it to six months, but I was having so much trouble, I had to phone and ask for an earlier appointment.*"

Part of the routine at the Cancer Center is to give people a card that contains the information about their next appointment. It was common for study participants to refer to this detail of waiting and monitoring their condition. Mr. Edwards mentioned his next visit, saying, *"He's on my little list here, yes I'm seeing him on a certain date.*" In many situations, the actual card was routinely placed in a prominent location in the home, where the message would not be missed. Jim spoke of "*putting his card on the refrigerator door, so it is right in front of him.*" Interestingly, at one point, after a few years, Jim and his doctor had both lost track of just how long he had been coming to the Clinic. "*Time has really gone by in a hurry, and I couldn't believe it was four years actually when he said, 'well, we'll go to six months now'. He asked me how long has it been, and neither of us were sure, so he went through his sheets two inches thick, and he said you're four years now, we're moving you to six months.*" Attending the Clinic no longer carried the same degree of potential worry for Jim, he felt more at ease in the environment.

Each person became increasingly more aware of the wide range of medical diagnostic procedures that are involved in monitoring the disease process. A most common reference was to a blood test that occurred with each visit. Some were more general in their comments, like Mr. Crawford, "*So they'd take my blood every other week [while getting chemo]. I would ask them what my blood reading was, and they said 'no problem'.*" Mr. Edwards talked of, "*Every three months I got a blood test, and the results of those blood tests were always very low numbers, sort of like .5 or is it .05, I can't remember. Very low numbers, but they bounce around, and they said 'that's normal'.*" Catherine, who was feeling some pain in her side, wondered if this meant the cancer was in her liver. When she mentioned this to her surgeon, "*he pulls out the blood test results and he said, 'It's as normal as it could be.*" Sharon understood when, "*For two years after that, there was nothing. It was good. I was going to the Cancer Center, there was no radiation or chemotherapy or anything, just the operation at that time. And then, the CEA rose, started to rise, and Dr. Ball was called in. There was a spot developing where my liver was operated on.*" People varied considerably regarding the attention they seemed to pay to this surveillance procedure: some were quite nonchalant; others kept careful account of the specific values.

Awareness of the critical role played by the lymph nodes was evident in many comments. Several spoke of either the presence or absence of lymph node involvement, in relation to the 'seriousness' of their disease. Mr. Crawford said, "*With those lymph nodes, one could have got away or*

something, even though they thought they got them all or something...you know what I mean, and they travel and all." Mr. Edwards noted, "*I think it was one out of 20 lymph nodes had cancer cells—and that is apparently good. If it was 5 or 6, that's not very good.*" Concern about the possible '*spread*' or return of the cancer was often noted. Jim spoke of a friend, "*This brought me back to focus again in that you may never ever be completely clear of cancer. His came back after some twenty years. And I've heard of a lot of other people now, who have had recurring cancer.*" Similarly, Mr. Webber said, "*So I mean the trouble with cancer though, it always suggests that you have an awful thing. You never know when you are going to get it back again, but he (the doctor) was very positive*". Linda was told, "*The chance of recurrence is 50/50. He told me this on the day he let me leave the hospital, and I was in shock again. He said it can recur in the same place or in the liver or the lungs.*" Since the relevant lymph nodes are not usually discernible externally, there was a sense of mystery about these sentinels of the state of one's health.

Included in this surveillance process was a series of radiographic tests, the significance of which became increasingly evident. As Mr. Crawford stated, "*Then I also had to go for an ultrasound. He wanted my liver checked and stuff like that...I think if it gets there you are finished. And the ultrasound came back clean. So Dr. Price phones me up and he told me, 'Bill, I can't find anything wrong with you. I have to give you a clean bill of health.'*" There was a feeling that perhaps the physician was surprised. Sharon's experience was

at the other end of the spectrum. "*They realized there was still something going on so they did another MRI and the CT scan. And they found something in here, but there was nothing else. So they kept an eye on it, and they did a bone scan...but I guess this is a pretty slow moving cancer.*" Similarly, Dolores noted, "*Well the pain starts and stops when it feels like it. But there's a swelling there, and I guess that's why the doctor wants to do this CT scan.*" The experiences varied with the individual. For some, the activities associated with 'waiting and monitoring' became mere inconveniences; for others, there was an ominous sense of 'waiting for the other shoe to drop', that is, for the cancer to return.

Both verbal and nonverbal aspects of communication, including what is not said, contribute to the individual's schema for knowing 'how they are doing'. One can imagine the relief for Isabel, who says, "*They do the exam (sigmoidoscopy) you know, and I can hear Dr. Ball say, from the end of the examining table, 'Well, everything looks alright'*". Catherine relates a slightly different experience, "*He examined me, and he said, 'There is a constriction there, and we'll dilate it and come back in two or three months.' I think he's waiting to make sure that it's well healed. I was afraid to ask.*" Mr. Crawford's description of the follow-up appointments was, "*He will look at [examine] me sometimes, and sometimes he'll just talk to me and say well, 'It is the same routine as the last time. If you don't hear from me in two weeks, everything is fine.' So they take my blood and I've never heard from them again.*" It is as if this lack of contact, serves as a positive announcement.

Frequent references were made to observations of a self-monitoring nature, and criteria were established against which progress was compared. As Isabel stated, "*You know, if I had the least bit of a sign of anything, I'm off to the doctor. And never leave it, not like some, for some that's terrible.*" Mr. Jones said, "*I was really back on track four months after I finished the chemo. My weight was back, and I was as strong as a bear. When I got the weight back that was the big thing.*" Similarly for Mr. Webber, "*I stayed on a sort of a multi-vitamin and I actually put on weight which they felt was okay. I think that part of it was I was home during Christmas and people were sending cookies and things over to us. I was into the Christmas cake.*" Both Linda and Jim experimented to see which foods they could tolerate. Linda talked of, "*I'm very careful about what I eat. You do have to be careful with an ileostomy. Over a period of two or three months my bowel system calmed down. I was up every night for the first two months, every two hours, and I don't manage well, with broken sleep. For me, that was terrible.*" Dolores spoke of, "*I used to like fruit, and now I'm a poor eater. Sometimes I crave chocolate and my appetite is now, well, it never was very good. I guess it's about the same.*" Mr. Crawford related, '*I was fine. That is, I felt good. You know I didn't bother about it again. That was it.*" For those people who were actively employed, such as Mr. Webber, having the stamina to return to work was important. "*I eventually got built back up [his hemoglobin] and just before Christmas I went back to work part time.*"

Jim recalled the significant events around this time, saying, "*So I went back to work and really had no difficulties but of course, I had a new life. I was living with a colostomy.*" Knowledgeable about the operative techniques to perform a colostomy, Jim also was attentive to the area of sexual function. He related his surgeon's words, *"Well, you know Jim, one of the things we don't know, is how you're going to function...*". Jim's own response was, "*Whoa!.so he got into it a little bit. And I said, 'Well, I guess we're going to have to wait awhile until I know.' Uhh, it, luckily it never was a problem, which is good... that would have been very traumatic. I feel very very lucky that it turned out that way because I know other people don't always experience that. They go home and then all of a sudden they get another knock.*"

Being unsure led to worry about what particular signs and symptoms might indicate was very common, particularly during the period of receiving either chemotherapy or radiotherapy. Mr. Webber said, "*One time I had sort of a sore aching feeling down here and by the time I told them, it had gone away quite a bit. They said, it wasn't related to chemotherapy. They said it may have been because of something I had eaten.*" Linda spoke of, "*I've had strange feelings now and then. It's hard to describe this. It's always in the pit of your stomach. You feel weird. And if you get a tiny nick or cut on your finger, it doesn't heal, and it just gets worse and worse.*" As Mr. Edwards noted, "*It takes nearly nine months to a year to get over that.*" Accessibility to the various health care professionals, in order to ask about certain changes or observations, was very important. Waiting for this new information to be

evaluated, and often times, having to undergo additional 'tests' was never a comfortable period of time. And so the cycle continued: tests, assessment by the experts, waiting for yet another 'pronouncement' of, "You're doing fine" or " I think we need to..."

SOMETHING IS WRONG AGAIN: STARTING OVER

At varying points during the Waiting and Monitoring phase, some study members became aware that the cancer had either returned or had never 'left' their body. Sharon, who at age 46 was the youngest of the participants, followed the recommended procedures for assessing her progress following the initial surgery. She related, *"And then for two years after that, there was nothing. It was good*". Unfortunately, a rising CEA level, and an MRI showed two spots on her liver. The 'spots' on her liver were removed 'successfully'. Once again, the cycle of procedures for monitoring was implemented. "*It [the surgery] seemed to stop it…, there was nothing…Things were going great and we had our year end. I worked right through January, February, it's always a tough two months. And I actually didn't feel different, but all of a sudden, one weekend, I went down to visit my daughter and I came back and I could not remember her name. We called the doctor, and he said 'keep an eye on her and we'll send her to emergency if something happens'. The next day I was reading some stuff at work, and I couldn't understand what I was reading. I couldn't remember and with someone talking to me on the phone, I couldn't understand what they were saying.*" Soon after, Sharon underwent brain surgery to remove a tumor. "*It wasn't in the brain, it was on the side of*

the brain. They did a biopsy, and it was cancerous. It was not separate. It was the colon cancer."

Continuing to attend the cancer center for another two years, Sharon recalled, "*But the CEA was still not going down, so he said we've got to see Dr. Simpson [oncologist]. I know that I had radiation for, oh gosh, quite a while. It seemed like heavy radiation. I kind of got really tired—lasted something like six weeks or so…There was nothing for awhile, and then a checkup with the doctor. You know, they didn't really let me go, I was always in touch with them. Uhh, the CEA hadn't gone down, right where my liver was operated on, there was a(nother) spot developing. They did some more checking—another MRI and the CT scan. They found something in here (pointing to abdomen). But there was nothing else. When they operated, they were able to remove one 'spot', but he found a 'spot' on the diaphragm. He couldn't, he didn't remove that. He said, 'I can't remove the diaphragm, you wouldn't be able to breathe. So he left it.*" By the tone of her voice and the look on her face, it was evident that Sharon was aware of the significance of this action. "*A few months later, there was another spot . . . in the lung.*" She went on to receive more radiotherapy, and as she said at the time of interview, "*I understand it was fairly successful. It wasn't longer in time (number of sessions), but it was longer in 'zaps'. I just forget how many.*" Eventually, "*Dr. Simpson introduced me to Dr. Smith and I'm on a program for chemo right now. And last week they told us, last Monday, or the Monday*

before, that the spots have gone to half size!" Sharon has now been living with the diagnosis of bowel cancer for eleven years.

Linda, diagnosed through surgery, commenced an initial treatment protocol, which included both chemotherapy and radiotherapy. When we talked later in the year, she said, "*And here it is December and I've only got, well I've got three more chemo treatments to go through: January, February, and March and reconnection in April. These doctors, the chemo doctors keep you on this timetable for a very important reason. When I went for my checkup (in September), I happened to see the chemo doctor first and he explained to me that I must go through the chemo first, before reconnection. I had understood that Dr. Henderson was planning on doing it fairly soon. Dr. Smith, the chemo man, said that if I did have the surgery first, then it is for sure six to eight weeks before they can start chemo again. If there is any kind of complication, that's more delay. This gives what's already in you a chance to mutate, therefore, the chemo they're going to give you is not going to work. No way, thanks, I'm not, no, I'm willing to, I've put up with this for this many months, I can put up with it a bit longer.*" Linda wants to rely on the recommendations of her doctors, but since there is some variation of opinion regarding the timing of the various interventions, she will follow the advice of the oncology specialists.

Linda described her treatment plan, "*In late June they started chemo for six and a half weeks of chemo and radiation. In the first and fourth weeks, are both of them. The first week of treatment—it's five days a week and then*

the second and third week, it's just radiation which means you're there for half an hour and you're gone. And then the fourth week, it's the same thing over again. By the fourth week, you're used to it and you feel more comfortable. But that first week was tough...Looking back, that was a tough week. I went out in the car on that Friday afternoon and I sat there and cried. Just emotional". As Linda summarized this period of time, "*I spent all of my days, I'd shower, I'd air dry, I'd go to the hospital for my treatment, I'd come home, I'd air dry (laugh), I'd put on more cream, have another sitz bath. That's how I spent my days. I found out that I could crochet on my back (laugh). I also had severe abdominal cramps and things from the radiation but I could cope with the Tylenol, that was no problem.*" One can sense that Linda was completely immersed in her treatment. At one point she "*had a minor blockage (of the bowel). I was doubled up (with pain) but they didn't admit me; I was okay but it was a minor blockage. They didn't give me treatments for two days because of that. They asked me 'shall we get going again or do you want to put it off.' I said, 'No, I want to get through this.*"

Although Linda did not make reference to the ongoing assessment procedures which would normally occur during the treatment phase, one can assume that regular 'blood checks' were taking place. She did recall, "*On the Friday before the September surgery, my radiation doctor, Dr. Simpson, checked me physically and he got rather excited. He went back and checked his notes and he said he couldn't find it. And I said 'what's the matter?' What can't you find. He announced, 'I can't find the tumor' And I thought, 'Wow!' So*

the following Tuesday after surgery, I think even Dr. Henderson was really surprised. He said all he took out was bits and pieces of it and scar tissue from the previous surgery." It is easy to imagine how elated Linda would feel, and what her expectations about 'recovery' might entail, as she said, "*I feel like I'm on the home stretch.*"

The next piece of news was not so encouraging. "*On the day he let me leave hospital in September, he told me that I was to see him every three months for two years, because the chance of recurrence is 50/50. I was in shock again...Just hearing that, I thought I don't believe what I'm hearing. He said it can recur in the same place or in the liver or the lungs. And I'm not going to let that happen. I'm going to fight this with every ounce of energy that I've got.*"

Sadly, Linda's cancer did return (or never really 'went away'). During a second interview, she relayed, "*Anyway in November, the next year, they diagnosed that it has gone into my lymph system, which is not good. Then in January, two years later, they diagnosed a rash on my abdomen and it is cancerous too. It's still the rectal cancer that I had before. But I'm not going to let this get me down...*" She had been aware since July that her leg was swelling. "*They all said that I couldn't take any more radiation. I said it was probably from surgery and the surgeon said it was probably from radiation. But now we've had CEA tests that show us that it is the lymph system that's causing the leg swelling. The cancer cells are in there. They're blocking the lymph system, that's why the leg is not going down.*" She went on to say, "*So*

my reasoning is that to get rid of the swelling I've got to get rid of the cancer cells." One can detect the sense of solitary aloneness that she feels.

Linda expressed frustration with the communications from various health care professionals during this particular time. "*They didn't tell me anything. They don't tell you anything. You just go from one test to the next test...Let's face it, they don't want to come right out and say, 'Hey, you're going to die 'cause we can't do anything else for you. Instead, they say, 'We can't give you any more radiation'. I just said, 'Good, I don't want it anyway.*" "*I think it's just that they don't know what to say to a patient...and because they [the nurses] don't know what else to tell a patient, they don't tell them anything.*" She was more positive regarding the comments from her surgeon and another physician, saying, "*Excellent, and Dr. Wilson is just the top of the heap. He's the most compassionate man I've ever met. He's really there for you.... I find that some of them [health care professionals] are getting more open to the ideas.*" Linda described this part of her journey with cancer as, "*I just feel that this winter I have been led on a pathway to hell. It's slightly annoying.... Let's face it, the cancer clinic people themselves take you to a certain point and then they can't help you anymore. So that is sort of like a dead end. Sort of like a brick wall. That's it. You've just. That's it.*" The pronouncements now are not the type that anyone wants to give, so they are not forthcoming.

Incorporating complementary therapies into her regime was a customary action for Linda. This was noted early on, and evolved throughout

her experience with cancer. As she stated, *"I'm certainly open and willing to try new things."* Linda expressed her views as, "*This alternative medicine, I wish that they'd change the name of that. The reason being that I found out recently that modern man has only about 150 years ago taken the body and tried to heal it separately from the mind and soul. And it doesn't work. We are not coming into new alternative methods; we are getting back to the tried and true alternative methods. Should get rid of the modern day medical. I'm not denying for one minute that they have done some wonderful things.*" Supplementing Tai Chi, the use of herbs, and dietary changes, Linda continued to add other methods/techniques to her repertoire. The therapies she tried included: acupressure, acupuncture, shark's cartilage, an aloe vera based intravenous substance, iridology, and reiki. It was her belief that, "*You can work all these things in together and heal faster.*" As time progressed, Linda talked at length about the complementary therapies.

Linda was not a person who had been actively involved with a particular religion or church throughout most of her adult lifetime. However, as she encountered this phase of living with cancer, she talked of, "*I really feel that I can be led in a certain direction. I talk to God and I still want to listen. A couple of times I know when I've got specific messages. And it has really helped a lot. One of my friend's favorite sayings to me was "Let go and Let God' and when I do that, it helps a lot. Unbelievable… My mind is getting stronger because of my belief in finding God and I don't believe in being a religious fanatic either. I've met too many hypocrites. I mean that spiritually, I*

feel more a peace inside." This same friend, who had recently died, also encouraged Linda to, "*think of rainbows, whenever I have some bad times. Rainbows are beautiful. It is one of God's miracles. Think about rainbows coming down through your head, through the whole body, think of it surrounding your body. And think about them connecting you with your loved ones, and it really works.*"

Meeting regularly with a group of people, who also were experiencing the recurrence of cancer, was important to Linda. "*Dr. Wilson put me in touch with the cancer support group and it has literally turned my life around. Before I was so down about everything, everything was not going well. We meet every week. Once a month is not enough.*" Linda talked of several self-help books that she and others found to be helpful. "*The 22 non-negotiable laws of wellness*" by Greg Anderson were being used to structure meetings of the group. It was felt "*that patients can talk differently when they know everybody in the room is suffering from the same thing they are. Even if it is different variations.*" The challenges involved in talking to one's family about serious matters were revealed. Linda said, "*No, my sons don't talk to me much about my illness. I am going to sit them down one day, cause I see the look in my oldest son's face. He's finding it tough I think. Cause he's a sentimental slob like I am (laugh)... Well, they know. We haven't talked that drastically about it, but they know darn well there's a chance I'll not make it, but I'm not going to let that control my life.*" Linda made this pronouncement for herself. At no time in any interview did she allude to 'giving up' or acknowledge that she was now

dying. There was still hope. Linda died three months following this conversation.

GETTING ON WITH LIFE: REFLECTING/ MOVING ON

People do not expect to experience life-threatening events. Such occurrences seem to 'come out of nowhere'. There is little preparation that one can pursue in order to be ready for such an eventuality. The diagnosis of bowel cancer initiates a series of events for which the outcome is unknown. Indeed, even the suspicion that certain bodily functions or sensations are not 'normal' causes a person to embark on a new avenue. If the individual has enjoyed relatively good physical and mental health until this point, it is likely that there has only been limited contact with the health care system and with various health care professionals. All this changes once someone "knows something is wrong". Fortunately, of the many people who receive the diagnosis of colorectal cancer, and undergo one or more of the common treatment modalities, most are able to 'go on with their life', in a positive way. Throughout our conversations, comments of a more reflective nature were often expressed. As each person mused aloud, it is as though they are trying to 'make sense' of this event, and to 'move on' with the living of life.

The majority of individuals in this study were near or in their '60's. From this vantage point, it was common to hear a type of '*c'est la vie*' (this is life) outlook expressed. When asked 'what helped?', Mike said, "*I don't know really. I think the best thing would be to have an Irish background and be bull headed, take everything as it comes. You've got to take it as it comes. The*

good with the bad." Several included the thought that they felt fortunate to be an 'older' person when diagnosed with bowel cancer. "*Well I guess I've always been a fatalist. You know what I mean. Why shouldn't I get it, that's what I thought (laugh). You know, particularly when you seen these young kids who have it and you know they are eight or nine years old, and you think, at least I've had a life. That's how I looked at it,*" relayed Nick. George commented, "*What bothered me the most was seeing some of these young people in there. I mean young. Too young, too young to have this. You know what I mean, eh?... Very young people. That kind of bothered me.*" Mr. Edwards said, "*I know that a lot of young women may have breast cancer and they die from it, or it may be in their family and some women have actually had both breasts removed because they don't want to get cancer.*"

Attempting to determine 'why' one had developed the cancer was often addressed. Sharon wondered, "Maybe 20 years ago, I was dieting really hard. I'd only eat about 400 calories a day! For six weeks, and I drank a lot of diet Coke, I don't know, maybe two big bottles of diet Coke a day. Another thing I used for maybe a month was Ex-Lax and I used that to get my weight down. I am wondering if that had something to do with it." Linda raised the possibility of an inherited predisposition: "My grandmother, my maternal grandmother, died of bowel cancer in 1929. But Dr. Henderson doesn't think, like it's too far away to use that reasoning." She had also heard from an alternative medicine practitioner, "Maybe God has given me this problem to make me pay attention and listen. I have a habit of talking and not listening. So maybe this is a big

sign to me to start listening." Later on, someone in her support group said, "They say if you can, look back. Look back through your life, step by step, and find some major crisis that you went through, and they say usually this is what causes cancers. Usually in about six to eighteen months." Linda then recounted a number of stressful events that had occurred to her and in her family in a relatively short time period. The idea that the cancer was linked to one's immune system was expressed. "It was the straw that broke the camel's back. My body was so, my immune system I suppose was so wacked out, that was just the last straw... I know exactly that's how it started...build up and build up." Jim said, "My recovery at home was good and speedy. I felt very strong. It was amazing that I probably hadn't realized how low my immune system had gotten. You know I was so busy, travelling back and forth, you get tired and you don't realize how run down you are getting."

The beneficial effects of maintaining a positive frame of mind were espoused by most participants. Isabel said, "*I came home and somehow I had this, I don't know what you could call it, but it didn't bother me much after that. I had this attitude of good attitude...it was good all along.*" As he was anticipating surgery, Jim reflected, "*I am a positive person. I went in with a positive attitude... I've never been one to dwell on the negatives. Being more positive is a big help. I think that your body also recognizes whether you are feeling up or down.*" Speaking of giving encouragement to a friend who was receiving radiotherapy, Mike offered, "*I just told him to 'keep his head up', and 'don't let nothing bother you. Just keep going.' Apparently he thinks of me*

often when he is up there, and the going gets rough." Linda's comment was, "*One of the things that's helped this last winter, is trying to think more positive. I have always had a natural tendency in my whole (life) to reach out and help people.*" Similarly, "*The doctor at my work said that I seem to have a natural positive outlook and I'm trying to capitalize on that. I don't know if it's because I really do feel good that I'm doing so well* " (Sharon). Mr. Edwards stated, "*I think you have to, first of all, you have to have a very positive outlook. Maybe I'm naïve, but I just never looked at cancer as being the big 'C'. To me it was just, if you want to call it something like that, it would be as a small 'c'.*"

Perhaps those who received a colostomy had the greatest adjustments to make. Sharon relayed, "*Well, it was something I was able to handle. You know, I didn't like it, but I handled it. I would lean over the sink, the basin, and you know, do what I had to do.*" She went on to say, "*If I had to live with it I would, but it's not the greatest you know.*" Jim talked of learning to care for his permanent stoma, "*You've got this change in your body... Now it's sort of just like shaving, getting dressed every morning, combing your hair, putting on your deodorant, or for a woman changing her makeup. It's just something that I do, I've got it into a routine... The big thing of course is some of the changes in your diet that you have to kind of watch. I didn't have to make too many adjustments. I've eaten pretty well everything I ever ate before. I am more careful about the types of foods that can cause diarrhea because that's the real problem.*" He went on to share some of the embarrassing situations he

has experienced, as well as the fact that he is still able to travel internationally with minimal problems.

The emotional impact of the diagnosis of bowel cancer is immeasurable. Jim said, "*Well, I guess, in the first instance, the biggest thing that comes to you is your mortality. And I hope that I have, I have come to the realization that we don't, we don't live forever. We don't have control of our destiny... You focus a little bit on your understanding of your mortality. And you know, that's hard because, I don't think that most people ever contemplate their mortality, really... maybe they do if something serious happens. We don't know how long we're here, so I'd like to try and make things the most enjoyable.*" Sharon was very direct, "*I think one of the things you have to do is stop and enjoy the day. Work, take one day at a time. Enjoy the sunset. Enjoy the birds. I go out in the yard and I never heard the birds before, but I hear them now. I love to watch them. It sounds dumb I guess, but just enjoy everyday as it comes.*" In like fashion, Linda expressed, "*There is a little poem that I just love. It's 'yesterday is just a dream, today is life, tomorrow is just a vision' Today is for living. Today is the first day of the rest of your life.*" Each person is confronted with the realization that one's mortality is under attack.

Recognizing the potential threat of the cancer, several individuals initiated specific actions related to long-range planning. Nick shared, "*Well, actually 'cancer', it, the word frightens everybody you know. So you think that your days are numbered, and this sort of thing, and you're glad you did things*

like you did...like look after life insurance and investments so that your wife will be looked after." Jim said, "*We did make preparations though. We talked about those things, and we remade our wills.... We talked about the negatives, but we just didn't dwell on them a long time. We sort of went over everything. My wife is not a person who has been left out of our financial planning.*" The diagnosis of cancer prompted people to 'take care of' matters that might, otherwise, have been left until another time.

A theme of hope permeated almost all conversations; only Dolores seemed to feel little optimism. She expressed very modest wishes for the future, saying, "*If we could just drive to some place in Alberta. We got a book and it tells all about different places you can go to visit you know. That would be ideal. That would be our retirement. We could go a day here and a day there, yeah.*" Linda looked forward to, "*spending more time together. We've had 30 years together, and we'd like to have another 30 (laugh)... He was always on the road. When the kids were small, I couldn't go with him. Now with both boys out on their own, there is no reason why I have to stay home. Except, I'm a home body. I'm one of those people that in the old fashioned days, would like a little white picket fence...*" Dreams for the future were not pretentious, focusing more on the 'simple pleasures' of daily life.

The necessity to have ones' hope supported by others was accentuated by Wayne, "*Don't take away all my hope. I need that. What you said might be true (re prognosis), and it might be the type of thing you would say in a medical doctor class, where you say, 'there is no cure for this*

condition and so he's 'gonso'.' But, as a patient in the hospital, I don't want to hear things like that. I want to think that I have a chance of getting somewhere. You don't tell the patient this." Even as Linda's condition deteriorated, near the beginning of an experimental drug program, she said, "*I think that it is working already. There are just little signs here and there that things are starting to work...It's going to take some time, but I feel confident that this is going to work for me.*" For Linda, the rainbow was symbolic of hope. She asked "*all of my friends and relatives, every time they send me a card or whatever, a little gift or something, it always has a rainbow on it.*" Surrounded by such mementos in her hospice room, Linda felt tangible hope.

As individual study members looked toward the future, how were they planning to spend their time? Initially, Sharon, Jim, and Nick returned to their regular employment; Sharon eventually retired in order to spend more time with her husband. Nick also anticipated "*cutting back on his work, arranging to have his children run the shop, and then possibly put it up for sale in the Fall.*" He said, "*I would like to do something that's light but keeps me active. Not a lot of hard work, but keeps me active, on a daily basis... just to keep me occupied.*" Perhaps one of the busiest was Mike, who even though he was 'retired', continued to "*shovel snow, do mechanic work, and a lot of carpenter work in the basement too. Oh, and I play a bit [a lot] of Bingo on the side (laugh).*" Jim and George were both eager to get back to their golf. Wayne also felt that physical activity was an important component of his life, "*I've always done cycling and swimming and I've tried always to keep myself in*

shape, and I've always tried to do some exercises. You just do a little each day." Returning to her pursuits of painting, walking and yoga were goals for Catherine. Sharon shared her interests. "*I'm going to take yoga, because I think that being able to meditate and that sort of thing would be good. I'm also going to take Windows'95 and Simply Accounting.*" Being able to do 'ordinary' activities was a source of anticipated pleasure." It is as if each person is pronouncing to all in their proximity, that there is a future for them, and this is what they plan to be doing.

As they reflected on learning to live with colorectal cancer and the significance of this experience, participants frequently voiced issues around the area of religion. In this particular group, there was only one person who attended church regularly, however, several expressed their beliefs in a 'higher power'. Isabel related, early on in our first meeting, "*Well, I'm Catholic, Roman Catholic. But, I don't believe in it anymore so I was with the Jehovah Witnesses for a long time but I'm not really practicing that either. To tell you the truth, I'm confused. I really am confused, but I do believe in God.*" George said, "*I go to church every morning, you know. I'm a Catholic, I might miss a few days, but every morning I try to go to mass, and thank Almighty God that he gave me a second chance. I can't think of a better way to start the day. No. I love life. I still intend to be around for a few years and enjoy life and everything else, you know what I mean.*" Jim commented, "*I'm not an overly religious person, but I have, we have strong beliefs. In the first three or four months [after diagnosis], there was sort of a rush of thoughts... about your*

mortality, how I felt about my spirituality, and how I felt about God. I constantly remind myself, when I have a moment to reflect. I think 'I'm very lucky, I've been able to continue to do the things that I think are important in life, with my family and with friends.' We're not big church goers, which has maybe been a mistake in a way... maybe we should bring that back into our lives." A similar situation existed for Linda, "*I've always believed in God. I've never been a church goer much. Maybe when I was younger. Got away from it a bit. Oh yes, I believe in God. When I saw the iridologist, she asked me if I was looking for a faith... I know somewhere along the line I've got to find a church, but she said I should find the faith first.*" Living with the life-threatening illness of colorectal cancer has the effect of initiating a closer examination of ones personal beliefs and values, including those of a spiritual nature.

Contemplating the significance of living with a serious condition, Jim commented, "*Life is not designed [specifically] for you. You have your time whenever it is going to come and you have no control over it.*" Later, "*I think to myself, well I just really feel very lucky. I guess I have another purpose to fulfil here.*" Linda, in spite of facing recurrence of her cancer, expressed, "*I'm down for a reason and I don't think I've fulfilled that yet. I really don't. Oh, I've had a good marriage for almost 32 years, and I've raised two fine sons, but I still feel there's something else that I haven't accomplished yet. I am seeking that purpose in life.*" Articulating the philosophy that perhaps there is a purpose or reason for one to acquire this cancer seemed helpful to some to accept the reality of the situation.

As she contemplated the future, Isabel said, "*I'm not that dumb that I don't know that it may come back someday. You know what I mean, there is a possibility and I know that. But in the meantime, I am going to be happy 'cause I don't have it, you know.*" Mike has had many friends who have died from cancer. He states, with resignation in his voice, "*We've been here since 1966; all our friends are gone. Cancer's already got them... quite a few of our friends died of cancer. Just the word is enough. It's kind of scary because you figure well, you're not going to be around that long.*" George wondered, "*There were a few people, taking the chemo, that underwent the same surgery as I did. I don't know, I hope they are doing well, you know what I mean. We were basically on the same kind of chemo.*" Jim also talked of, "*a very good friend of mine, his wife had been diagnosed with breast cancer, and she died very quickly, just recently. I sort of thought to myself, 'why her and why me?.*" One senses that George and Jim are well aware of the statistics on survival with colorectal cancer.

People 'move on' with their lives. Is there a conscious integration of this experience of living with colorectal cancer? Or do the surrounding events merely fade into the background? During the period of data collection for this study, no one has yet reached the 'magic' five-year anniversary. At the five-year marker, if there is no further evidence of cancer, a person is pronounced 'cancer free'. One wonders if the person ever really forgets about the cancer?

Learning to live with colorectal cancer does not occur in isolation. Relationships with health care professionals and support from family and friends are key.

RELATIONSHIPS WITH HEALTH CARE PROFESSIONALS

Woven through each person's description of the events associated with a diagnosis of bowel cancer are many references to the various members of the health care professions and how each one contributes to the context within which these events occurred. Doctors and nurses, working in many different settings, were most often mentioned by all participants. While the commentaries are largely complimentary to the health care professionals, there are also depictions that are more negative.

Study members generally spoke of their family doctor and the surgeon by name. This is reflective of the close relationship that develops very quickly between the person and the physician(s). Catherine said, "*I've known my doctor for well over 20 years, so I know that I can read his mind... like he poo poos me when things aren't too bad, and when it's serious, he's serious.*" Referral was made to surgeons and oncologists thus the focus of most discussion was on the interactions with these specialists. Mr. Webber spoke of, "*It was all set up through Dr. Todd, and he put me in touch with Dr. Smith over there [at the cancer clinic*]." Linda's experience was similar, "*My family doctor first discovered the rectal growth, and then he sent me to the specialist. I was there in an hour and a half. He confirmed it, and said, 'you're going to the hospital.*"

How does one form an impression of this person to whom you are entrusting your body, and perhaps, even your life? Sharon speaks of Dr. Ball saying, *"(He) spent a lot of time with us talking, and I had complete confidence in him... I knew it was a major, a major undertaking. It was aggressive surgery. But I think because I trusted him so much*". Isabel described this same person as, "*Very caring... compassionate is the word, very compassionate, he's got great bedside manners.*" It is clear that the primary form of interaction is based on the verbal communication between the patient and the physician. As Mr. Crawford's doctor said, "*We have to get rid of it, the sooner the better". I was all in favor of that and I knew, he sounded like a real good doctor. So I knew I was in good hands. I wasn't even afraid the day of the surgery. I had all the confidence in him.*" Sharon stressed, "*He talked to Ralph and myself, and he was just excellent*". The inclusion of her spouse was also important to Linda, "*Bill happened to be there with me so he told Bill and explained it to him too.*"

The frequent references to the professional's communication style gives credence to the emphasis that is placed on this facet of the interpersonal relationship. The dominant expectation was that the doctor would be "*pretty straight forward with me, and he went on to give me a lot of information on what to expect. He was giving me a lot of encouragement though.*" (Jim). Linda said, "*Dr. Henderson is the kind of doctor that tells you everything up front. He doesn't give you any false hopes. He told me the straight facts. He draws me diagrams, he's not a good artist. He agrees but*

he draws me diagrams to explain what he's doing or what's he going to do." She added, *"About the second day in hospital, I had a list of questions by this time. He said, 'I just love people with lists'. I also felt with Dr. Henderson that he wasn't looking at his watch thinking what will I be doing with my next patient. He was there for you".* Mr. Crawford expressed his sentiments as, *"They didn't withhold anything from me. I mean if they had something to tell me, I didn't have to ask them. I never walked out of there thinking that they were keeping secrets or holding something back. They were pretty straight forward you know. I felt good."* Forthright, honest, open, and clear communication was essential in the relationship of each person to the individual health care professionals.

In addition to assessing the physician's abilities to communicate the technical aspects of the surgery required, and his experience in this area, people alluded to the type of association that developed between them. Perhaps most eloquent was Isabel, *"I guess it was his personal—he didn't take me as a number, or like that. It was an individual liking between us, you know. Shaking hands and being so personal and close, not distant. He showed me that he was a professional but in the caring way."* Interestingly, one way in which this connection was facilitated, was when the physician shared a part of his 'private' life with the individual. *"Dr. Ball is so nice, he tells me about his family, and he was concerned that I had to wait one day. He's a wonderful man. Some people put doctors up on a pedestal, along with the priest, or whatever, not me. I talk to them like they're just my friend, you*

know." What might seem to be trivial and insignificant comments take on new meanings. Linda, speaking about giving her medical history, "*One of Dr. Henderson's doctor assistants was asking me these questions, and he said, 'oh, you've got a great birthday'. I asked 'why'. He said, 'cause it's mine' and laughed.*"

The notion of 'partnership' was evident through several statements. Jim talked of, "*There was sort of a team of Dr. Good, Dr. Todd and Dr. King...*" Sharon said, "*I remember walking down to the operating room, the nurse had to almost drag me in. But it gave me a feeling of being part of the team.*" Catherine also recalled, "*They wheel you into another little waiting area, and then you go into the OR. I was introduced to everyone there—this really impressed me. I hadn't seen the anesthetist before...so I met him, and the circulating nurse introduced me, both scrub nurses were introduced. Dr. Todd came and talked to me. I was wide awake, none of this pre-med stuff.*" Study participants conveyed that they felt valued as individuals by the physicians who were their primary care providers.

Recognition of the commitment of the surgeon was acknowledged by Jim, "*Then Dr. Good came in. He was very good, he was in and out all the time, every day. He'd come in the evening too. He'd sit down on my bed and talk to me and things like that*". Mr. Edward's recollection was "*He's in there early early in the morning. And he goes home late late at night*". The fact that the surgeon was so available definitely had the effect of enhancing the person's confidence in the medical processes.

While physicians were most often talked about in relation to the diagnostic and surgical phases, nurses were the health care professionals linked most closely to the adjuvant treatment phase, whether this was chemotherapy or radiotherapy. The primary characteristic, mentioned by several participants, was the general positive atmosphere created by all the Cancer Clinic staff. As Sharon said, "*We even enjoy going there. They've got such a good attitude there. They wave to you when you come in. The nurses, the oncology nurses, are wonderful. I guess they are specially picked for their attitudes, but they joke and kid and tell jokes and everything. They are just wonderful. They're up all the time.*" Her husband added, "*There's always a smile... or a joke, it's a happy place.*" Isabel, who was single, said, "*They were so good to everybody. They were like little mothers, you know just taking care of you, and calling you these pet names, and you know it was wonderful.*"

A sense of humor was valued greatly by all. As Mr. Crawford stated, "*All the nurses in the Cancer Center, in the chemotherapy, they can't be beat. I mean they are just top notch. I mean they're always full of, there is nobody down. They're laughing, they're joking, and they're smiling. To them, there is nothing wrong.*" Mr. Jones talked of the "*friendly atmosphere. We used to tell stories and everything else. It cheers you up for the day.*" A sense of humor was always viewed positively. As Isabel related, "*One of the nurses said that 'he's (the surgeon) good looking too'. So I told him that all the nurses were saying this. He just laughed...*"

Demonstrating technical skill such as inserting the intravenous needle in order to receive chemotherapy was also critical for these individuals. Mr. Webber said, "*The part that can get you are the needles in the hands. Because after awhile your veins, I guess you get little blocks or little scars. Then they have difficulty getting the needles in and so after thirty of those you have about had enough. Some of those nurses can do it almost painlessly.*" Linda expressed her appreciation, "*The chemo gals like to put the needles in your hand but I said look I like to crochet, so they put it in my forearm instead.*" Mr. Jones appreciated the abilities of the nurses, "*They are all really good. There is no kick on anybody up there at that center. Not one of them. They know their job and they do it well, I'll tell you. There was not a stone left unturned by those people up there.*" This confidence in the nurses' knowledge and abilities seemed to translate to a form of trust. As Mr. Webber relayed, "*I just did what they told me and it didn't bother me too much.*"

Mr. Edwards said, "*They're very sympathetic and they always try to help you. They're always asking if you are okay—they are really a good group in that regard.*" Mr. Webber spoke of, "*They are so supportive... especially if you are having problems. There was a gentleman there when I was in the last day, who was really reacting and they can put on a topical anesthetic or something. You've just got to talk to them.*" Isabel said, "*I think they are taught to do those different things, I don't know. But they are just really professional*". Staff at the cancer center were talked about as a group, not by specific names or by treatment areas. It is possible that because the time spent in the

radiotherapy area was much shorter, the opportunities for study participants to chat with the staff were more limited.

The three participants who received 'ostomies' were unanimous in their acknowledgement of the help received from the enterostomal therapy nurses. Jim spoke, *"Brenda was very, very good. It was because of her persistence, and she came in every day, at about 10:30 in the morning. She said, 'Now I want you to do it yourself.' I thought, 'Oh, I don't know, it's too sore.' She gave me a lot of confidence... told me I was doing well, again she was very supportive."* Sharon said, *"I had quite a bit of help. They showed me how to change it, how to disinfect, or whatever."* Linda emphasized, *"Marlene was fantastic. She showed me how and I actually did it, but she was there supervising, and it's so easy, you know, when they are there."* Appreciation for expertise in this area transferred to the Home Care nurses when Linda was at home and having problems with managing the ileostomy. *"Those Home Care nurses were wonderful. We timed it so that she would arrive just after I had my shower. God bless those ladies, they were wonderful. The hardest thing was coping with changing this stupid thing. It was taking me up to an hour and a half to do this. It was driving me mad."* She eventually was able to complete her shower and ostomy care within forty minutes.

Volunteers also provided valuable support. Following his surgery, Jim said, *"I had a chap come in and visit me on the fifth or sixth day, and he had a colostomy. He went over a lot of the things that he had experienced—some of the bad experiences. But the fact that his was now six or seven years ago—*

he was very supportive, and said, 'you don't really have much to worry about." Dolores talked of, "*There's the, I guess they're volunteers. They come around with coffee, tea or whatever, cookies... everybody's very nice over there.*" Personal contact with people who understood the situation served to augment the feeling of being 'cared for' as an individual. One is not just a 'case' or a 'number'.

Comments that reflected less positively on health care professionals in general, were very limited from these ten individuals. However, the concerns raised need to be cited. Sharon's situation was such that her family doctor had difficulty determining the correct diagnosis. Unfortunately, over the course of approximately three months, Sharon's symptoms became much more intense. When she finally was seen by a surgeon, it was necessary to perform a temporary colostomy. Several years later, the cancer reoccurred. She said, "*Initially, there was no blood. Maybe that's the thing that tricked them."* Sharon and her husband had considered filing a malpractice suit, however they also recognized those *"other doctors who were just excellent and saved her life". They expressed the idea that "I've got to trust these other doctors. They're not going to want to touch me if... they would say, 'Don't go near that one*.'" Similarly, for both Linda and Mr. Edwards, whose symptoms were not 'clear cut', approximately six to twelve months elapsed before a definitive diagnosis was made. Linda seemed to accept that it is not always easy to determine what is wrong with one's body. Mr. Edwards talked of "*This doctor did an examination [colonoscopy], and apparently gave a report to my*

GP, which I never did learn about until after my colon operation. My GP was supposed to follow up, which he did not do... I didn't get the proper treatment right away." As one listened to Sharon and Mr. Edwards talk, it was very apparent that there was anger, dismay, and lingering anxiety related to the delayed diagnosis. The unasked question was, "Will this delay in diagnosis result in more problems for me?"

Mr. Edwards attempted to understand how the planning of operations was handled in the hospital system. In doing so, he initiated a phone call to the Health Department. As he said, "*They phoned back to the proposed surgeon, and I don't think that person liked the interference from Alberta Health about the scheduling of cancer operations.*" He could tell that someone was annoyed. Another, particularly poignant vignette from Mr. Edwards: "*This is a dandy. Here I am about one week after the operation. One of the resident doctors who had been coming around with Dr. Ball came in with another young man who might have been an intern and they were talking about my condition. They left, and then the young one came back in, apparently he had participated during the operation. He said to me, 'There is no cure for this', and he went out. Just bluntly like that. The next day I told him that I don't think that what you said was the right thing because you've taken away all my hope. I said, 'I need that—I want to think that I have a chance of getting somewhere.*" Fortunately, Mr. Edwards is an assertive person and did verbalize a response to the student physician.

Dolores talked of her lack of medication, "*They sent me home with no medication and the pain was unbearable. Of course, the home care nurse couldn't prescribe anything. And we are kind of shy people, so we didn't phone the doctor back to ask.*" Isabel identified a different issue when she spoke, "*I had to go and see this woman. I don't know if she was a nurse or not, but she asked me how I was feeling. I said 'okay, but I'd like to talk to some sort of a group, you know a supportive group.' She said she would see what she could do, but nothing ever came of it.*" The notion of 'unfulfilled promises' is evident. Just as people formed impressions that were affirming based on seemingly, small bits of evidence, similarly, these brief sketches illustrate how other minor exchanges could have major significance.

Only infrequent references to any form of complementary therapies were made. Catherine, who knew her family doctor well, talked of letting him know "*I've got the name of a naturopath and what do you think? And he said, ahh, it probably can't hurt.*" She also said, "*I think that when you have cancer, you have to really make sure that what you think is happening, is happening, before you start looking for alternates.*" Linda approached the oncologists at the cancer center about '*taking herbs*'; she was surprised when they both said '*No*'. She said, "*When they said don't take herbs I thought okay. I have to go through the chemo and radiation because I have no choice. I don't want to take a chance and screw things up by complicating things. For now, I'm following orders. But once I'm through, I'm not going to stop there. I'm getting back into my Tai Chi. I'm going to be taking herbs, I'm looking more into*

herbs. I bought myself a juicer last night... I'm not going to stop. A friend of mine loaned me a book, 'Sharks Don't Get Caught, Sharks Don't Get Cancer'." It would seem to be a positive measure of the nature of the relationship with the physician when the person with bowel cancer volunteered such questions.

Without exception, the participants included references to the important roles played by the various health care professionals, throughout their comments. It was as though the two were inseparable: the experience and the people who helped each participant get through this experience.

THE CONTEXT OF SUPPORT: FAMILY AND FRIENDS

Although it is an individual who is diagnosed with bowel cancer, it was rare for someone to experience this event in isolation. The pronouncement of cancer, of any type, initiates a cascade of events, thoughts and actions by the person affected. It seems to be widespread that a person will reach out to those around, in order to share the burden of this, initially, devastating revelation. The study participants clearly articulated that 'getting through' occurred with the support of family and friends.

Eight of the ten participants had a spouse who provided substantial support; all study members were in regular contact with their children. Some people referred often to these individuals; others made only limited reference. All five men mentioned their wives, particularly in reference to making decisions or accepting the recommendations about treatment. Mr. Crawford said, "*She [his wife] definitely wanted me to have the surgery, that's for sure.*

And she was probably a little worried when I went under the knife. When I came out of it, she was fine. What I mean, she's accepted it. It hasn't changed anything in any way, shape, or form. I guess she's quite thankful that I'm still around (chuckle)." Mr. Jones commented, "*I had a lot of good backing from the wife too. She kept me going. She kept bugging and pushing and it helps quite a bit, I'll tell you. The wife would do the asking of questions, and then tell me.*" Throughout her commentary, Linda made frequent references to her husband and sons, "*It's incredible, you know. But I've got the best husband in the world and I've got two very supportive sons.*" Mr. Webber's wife was employed in the health care field, and her special knowledge was most useful.

In particular, the three people who received an 'ostomy, all noted their spouse as being very helpful to them in making this adjustment in their lives. Sharon spoke of, "*I think that one of the things that really helped me was my husband's attitude toward the whole thing. He was very good.*" Jim talked of his wife coming in to the hospital to learn the mechanics of caring for the ostomy, "*Lynn was there one day, right at the time with the [ET] nurse. She took it all in.*" At home, when there was a nighttime accident, he appreciated her '*matter-of-fact*' attitude and the '*don't worry about it*' at 3:00 am.

Comments regarding the support role provided by children were more limited, but nonetheless significant. Each participant eagerly outlined the structure of his or her family, naming individual sons and daughters, and in some cases, even grandchildren. Mr. Crawford said, "*The surgery was on my*

oldest son's birthday, and my second grandson's birthday." Isabel mentioned that "*her daughter accompanied her to the teaching session about chemotherapy.*" Catherine spoke of, "*After Chris (her stepson) left, by the time he got to his office, he had phoned the whole family. That really helped.*" There was a general sense that the children were there for them, giving encouragement along the way. Sharon related, "*I remember my daughter and I went into the store one time, and it (colostomy) would make a noise, and it would also smell. So, this happened and the sales guy was saying, was kind of looking around to see what he could see (laugh). So my daughter just said, 'Did you hear that?'. And he just laughed...*"

The family relationships for these study participants represented a variety of situations: traditional, divorced, and stepfamilies. The adult children were either living close by or at considerable distance. Most described themselves as '*happy*' families; others had tensions of one kind or another. There was evidence that, at times, the parent diagnosed with bowel cancer attempted to shield children from some of the concerns. As Sharon said, "*I have a son and a daughter who are both in the city. But my daughter and I talk a bit more than my son. I try to protect my son.*" The idea of protecting one's family members was also conveyed by Linda, "*Sometimes just coping, just getting through the day, was a full time job. And some days, I just, I had some bad days. But it's funny, usually if I had a crying session, I'd get it over with before Bill [husband] came home from work. But one day, he caught me at it.*" Isabel expressed, "*My kids are so good. One works all over the world.*

Very supportive, yes. But I don't see as much of my boys as I would like because they are so busy... busy making money." Catherine noted the varying responses of her family members, "*You know like everybody in the family approaches things from a different direction. My grandson came right out and asked, 'Are you afraid?'*" Of his sons, Jim said, "*They may have spoken to Lynn. I don't know. They tried to be upbeat. We talked about it much later. Mike is more, more reserved, maybe more like myself and doesn't express everything. If it's something he doesn't want to talk about he'll probably just hold it in. Whereas John just gets right out with it—wears his 'heart on his sleeve'. He was constantly checking on me, he had to make sure I was okay. But I felt everybody was on my side.*"

The importance of having someone to talk to during this challenge to one's health was noted. Isabel, who was divorced, said, "*I probably told too many people that I had cancer because it made me feel, oh, it made me feel good to talk about it. You know, I had to tell somebody and I was telling all my friends in here when I'd meet them in the elevator, or sitting down playing cards or something.*" Sharon stated, "*My friends were all very supportive. My friends know me and they know that I like to talk about it. It's not a secret, you know. There were a few people I could talk to and they weren't afraid to talk about it or whatever.*" There is a hint here of the hesitancy that some people feel when the diagnosis is 'cancer'. With a disease that is potentially life threatening, many are reluctant to raise the topic. Linda emphasized, "*I would like to say that no matter what, like in the brochures and information sheets*

they give you, they suggest you have a friend or family member with you (as begin chemotherapy or radiotherapy). I would say insist on it. At least for the first day, and preferably for the first week. I had no one with me. I realized that I was the only one by myself. There were people who I could have asked—even a different friend each day." This was confirmed by Mr. Webber, "*And the first time Gayle went with me and that was good, because I did a lot of wandering around in that big building.*"

Extended family and friends were also very significant. As Jim commented, "*You know, the support of the family. My brother and sister's visits, and Nick's, and Nick's family, and all kinds of people. I mean I was absolutely amazed.*" Catherine said, "*This time, I phoned people and I told them (re diagnosis). I called our new minister. I called my friends. I told everybody. And you know, that is really really important… to let your support people know. You have to sort of say to yourself, 'yeah, I need some help here'. I don't need them to necessarily come and do anything but I need them to know. I need to know that they are out there praying for me.*" The notion of how one's connections with particular friends changes over time, is alluded to by Linda, who says, "*No, I didn't know many people up there. I have friends there now but of course, they are not close friends like we've had here for years. I had no real... for me it takes a little time to get to know my neighbors and because we were away most of last winter, I really had not got to know them at all... so it was tough that way.*" The network of emotional support extends beyond geographic borders. Mr. Webber, in an effort to obtain more

information about the treatment of bowel cancer, even phoned his cousin, a doctor, in England.

In addition to the sense of morale building conveyed by friends and family, there were instrumental activities recognized by the study members. Isabel had a close friend who, "*...does everything for me. He's going to start washing curtains, he did that last Fall. You know he does everything. He came to turn my mattress today—he just lives one floor down.*" Catherine talked of "*My sisters gave me a lot of loving input. One of my sisters had a party for me and invited all kinds of old friends, university classmates and so on. And I needed that too... it was really good to have the whole setting.*" Mr. Webber's friends, "*all offered to help, like Mike, who has been through it all, offered help. Can we drive you? Can we do this? Can we do that? They were very supportive. A lot of our customers offered to drive me down (to cancer center).*" The offers to 'do something' for the person with cancer were particularly appreciated as the weeks of treatment continued, and as side-effects were more pronounced.

Several individuals spoke of the support that was transmitted from the receipt of greeting cards during their illness. Jim said, "*I really was flooded with cards. I forget how many I had... but it was over one hundred.*" Linda, who had lived in several locations during her thirty plus years of marriage, reflected, "*I didn't know I had so many friends. They've all been phoning and writing me cards. Sometimes even two cards from the same lady in one week; even letters from my male cousins and men don't usually write.*"

Receiving news of this emotional 'caring' from near and far seemed to have the effect of bolstering the resolve of the individual to '*tough this thing out*'.

The concept of 'positive thinking' was prevalent. It is as if each person felt the need to be a source of 'self-support' and to think positively about the ability of their body to 'fight off' this unwelcome invader. Isabel put it this way, "*I had such a, oh I don't know, where it came from, this strength and the attitude I had. I wanted to fix myself up and go out and look as good as I could... I exercise, I try to keep myself in form, and as fit as I can.*" Jim was quite direct, "*I think being positive was a big help to me. I think your body also recognizes whether you are feeling up or down. The people who visited with me were the very same way, so it was a big help. They said, 'This can be beat.'*" Catherine had some long time friends who "*came and did a 'love in'—bringing lunch, treats and good wishes*" for her prior to her surgery date. Mr. Webber, while receiving his chemotherapy treatments, said, "*I had a feeling that your mind can really help you control things. You try to put your mind in a positive frame. So I just try to do it that way. If I felt sick, or tired, I just tried to tell myself, 'don't be so blooming tired'.*" His approach to recovery was one of, "*I think that if you have problems, you just have to deal with them. I like to keep doing something. I'm a firm believer that if you sit around watching TV, you are not going to survive.*" Pessimistic thoughts are not to be encouraged.

Linda was a person who actively sought activities that helped her create a 'positive' mind set. "*I am an avid member of the Tai Chi here, and it's really good for you physically and mentally. That is why I want to get back into*

it now. I went yesterday. It's slow and gentle, you don't have to strain yourself. It's really really good for you. You're opening up all your energy flow lines." She also mentioned that she is "*a great reader*", as well as the fact that "*I have a craft bag that I carry always -a craft or some kind of book. So I always have something to do.*" Linda found these interests to be especially helpful as she received the chemotherapy. It was her belief that these affirming thoughts and productive pastimes created a beneficial effect on her immune system and her body's ability to rid itself of the cancer. "*When I was taking radiation, I was doing visualization. I did this on my own. No one told me to do it. Every time that buzzer went, which means they are doing the radiation, I was visualizing a huge hot air balloon. Picturing it just big as it is, and gradually shrinking and shrinking, shrinking down to nothing, and it's gone... symbolic to me of the tumor shrinking.*"

A form of support that is based on the sharing of experiences with others who have 'been there', was referred to by some participants. Isabel expressed her ideas as, "*To see what they felt, and what kind of operation they had. You know once you've had that cancer, you always wonder, did you go through the same as I did and things like that. I don't know...*" Jim said, "*I certainly got a lot of encouragement from all the people that I talked to about it who also had had cancer. You find out about a lot of people who have had cancer, and a lot of people who have ostomies and ileostomies…people I knew quite closely in the business world.*" Jim also enjoys golf, so he was pleased to learn that '*several fellows who play on the senior PGA golf tour*

wear colostomies also." Unfortunately, not all comments from others are reassuring as Mr. Webber relayed, "*You really wonder about some of the things they say. They should be careful because everybody has this really bad negative view of chemotherapy in particular. I've had people say to me, 'Oh God, I had a friend who had chemo and they just refused to go in after the first three sessions.' It's like there is life on this side of purgatory and all this sort of stuff. I thought, holy crow.*"

The reading of inspirational kinds of books was advocated. Sharon spoke of, "*I had a book from work and it was on imaging and visualizing. I read it quite awhile ago, but one talks about that as well. Another one, although I don't know if everybody agrees with or even if I agree with everything he says, but it seems to be good is the Bernie Siegel book.*" Mr. Edwards shared comments on "*a little thin book. He was talking about his experiences in the hospital, and how nursing staff related to a person. I could appreciate it, because I was on his side of the fence. He got scared because he had cancer. I could relate to what he was saying, he put in words some of the things I was thinking,*" Mr. Webber said, "*Someone suggested a certain one to me. I think it was Gayle. It was 'Why do bad things happen to good people?'*" He viewed this as a 'do-gooder book', and because he "*was not a great reader*' did not acquire it. "Living life on purpose" by Greg Anderson was recommended by Linda, and was also used as an organizing framework by her support group.

It would be inaccurate to convey that all those diagnosed with bowel cancer invariably had a completely happy and harmonious family situation that provided them with constant emotional bolstering and a sense of well being. Several individuals were experiencing serious problematic situations simultaneously. Mr. Webber was concerned about his business and was uncertain about financial aspects of the lease. Catherine worried about her husband's care while she was in hospital and convalescing. Linda and her husband were still grieving the accidental drowning of a son from his first marriage, another son was experiencing serious visual problems, and her husband's work necessitated him being out-of-town regularly.

The context of family relationships and friendships enables the person to feel that they are not 'in this battle' alone. There are others who care about them, and who are able to provide a sense of support through an infinite variety of actions and comments. The significance of these forms of support is immense. In addition to the critical bracing of both one's physical and one's emotional self by family and friends, other relationships with relevant health care providers are developing concurrently. It is as though there exists another type of pronouncement, "We will help you get through this."

Analysis of the stories from these ten individuals provides a framework for understanding the basic social problem of how one learns to live with colorectal cancer. In the following chapter, I will outline the emerging substantive theory.

Chapter 5

THE THEORY

The question that began this research was "How does a person learn to live with colorectal cancer?" The query was based on fundamental beliefs that individuals are actively involved in dealing with their disease, and that while the diagnosis of colorectal cancer represents a significant health threat, there are many people who continue to live life well, even after the diagnosis. What is not known is how this process unfolds. Through analysis of data it was discovered that the basic social problem that each person confronts is indeed, how does one learn to live with colorectal cancer. The basic social process used to contend with this problem is 'self-talk: the inner work of illness'.

Closer observation reveals that the basic social process of 'self-talk' occurs in response to both 'internal pronouncements' and 'external pronouncements'. Internal pronouncements are made to oneself, either independently, or in response to announcements made by others. External pronouncements are declarations made by others, which profoundly influence the nature and process of 'self-talk'. These pronouncements are definitive, and elicit an internal response. Each pronouncement marks the transition to the next phase of the process, influences the nature of the self-talk that occurs, and signifies a turning point that serves as a precursor to subsequent action(s).

Analysis also revealed the presence of an eight-phase illness trajectory that served as the organizing framework within which 'self-talk' occurs. These eight phases occur within two major contexts: relationships with family and friends, and relationships with health care professionals (see Figure 1). Although 'self-talk' with its internal and external pronouncements seems to clearly be affiliated with particular phases of the trajectory, it must not be assumed that these are distinct, arbitrary, or linear in nature. There is persistent movement back and forth among the phases. It is the individual's interpretation of the situation, which is most important in determining the nature of this 'self-talk'.

Acknowledging bodily sensations: Knowing something is wrong

Most of us take our physical bodies for granted, never giving much thought to the complex activities: breathing, metabolizing, secreting, thinking, which occur minute by minute in order for us to feel well. It is often only when something happens that is out of the ordinary, that one is jarred into paying attention to the sensations of the body. When a person is compelled to take notice of a new or unusual sign, there follows a process of determining just how much attention one is going to give to this change. The 'self-talk', related to acknowledging that something is wrong, includes mainly a series of questions. Will I just 'wait and see' what happens? Is it becoming more uncomfortable? Is there anything else that is different? What's normal? What do I already know about such a symptom? Do I need to consult with anyone?

Given that matters related to body elimination are considered very private in our culture, it is most common for an individual to keep any new observations or different feelings to him or herself. Even though the gastrointestinal system is said to be the 'mirror of the body's emotions', a person may often experience slight

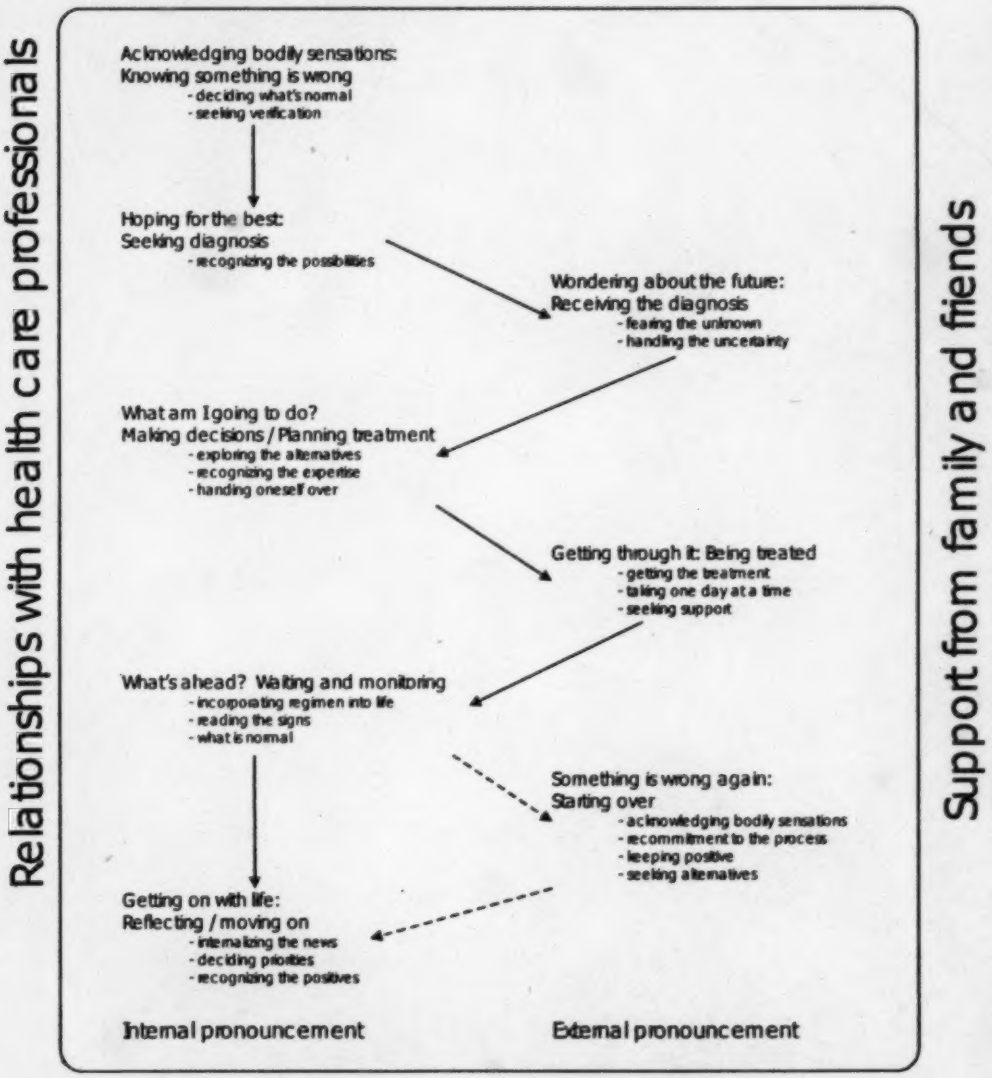

Fig. 1: Self Talk: The inner work of learning to live with colorectal cancer.

alterations from the usual, without thinking it is indicative of a serious problem. Relevant observations, as well as experiencing the continuum of unpleasant sensations from mild discomfort through to distressing abdominal pain, lead to a questioning. Some may be able to feel an internal lump. These observations and perceptions, while somewhat variable, are very real. The extremely insidious sign of gradual declining energy may be noted, but generally it is only in hindsight, that the significance is realized. As with each separate body system, there is a great range of associated signs and symptoms, and an equal variation of personal responses.

Telling oneself that these troublesome symptoms may be important is a first step in realizing that the body is not functioning at optimum capacity. The 'self-talk' results in the internal pronouncement of 'there may be a problem', what is going on is not normal for me. Awareness of the common signs of cancer, however imprecise, when combined with acknowledgment of one's own situation, serves as the impetus for consultation with others. The ensuing step seems to vary, dependent on one's relationship, situation and/or gender. One person may tell family or friends, another may keep it to him/ herself. Whichever course is followed, there is a beginning search for verification of something not normal. This seeking verification leads to an appointment with a physician. Sharing one's personal concerns, whether with a spouse, or, for others, by phoning for the appointment leads to validation of the internal pronouncement, "I need to get help."

Hoping for the best: Seeking diagnosis

Once the pronouncement, "I need to get help", is made, appointments are sought quickly in hopes of being seen by the physician in a short period of time. It is now that the issue of time and waiting begins. Although the wait for this appointment is usually quite brief, any delay becomes stressful.

The visit to the family physician is promptly followed by referral to a surgeon specialist, and plans for the pertinent diagnostic procedures are quickly implemented. A definite sense of urgency is conveyed. On the positive side, the person recognizes that the health concern is being verified and appropriate steps initiated, without delay. However, this brisk action adds to the emotional anxiety. There seems to be little that can be done to diminish the apprehension. If by some chance there is slow follow up, one's concerns are heightened. The person hopes for the best, all the while wondering what's ahead.

All the investigative procedures are unpleasant, offensive, and disagreeable, but in order to obtain an accurate evaluation, one submits to multiple indignities and discomforts, "I must do this". During these appointments and procedures, one learns some of the associated language used by professionals to describe the problem: medical terminology, which prior to this event was not applicable to you. The hunt for clues and evidence progresses. What does it mean? Many physicians now include comments about the likelihood of 'finding cancer' as an integral part of the initial meeting with the individual, giving the person more time to adjust to this prospect. One

awaits an external pronouncement, all the while thinking about the range of possibilities.

Wondering about the future: Receiving the diagnosis

The self-talk associated with managing the fear of the unknown, and uncertainty about the future is intense. On one hand, 'it may be something minor'; on the other hand... you don't want to think about that. The individual knows that one should be rational, but this is a most difficult state to achieve. Undoubtedly, the most poignant moment is when the doctor says, "you have cancer": the external pronouncement. A name is given to the symptoms. The name evokes fear and anxiety. Even if one has been well prepared for the possibility of this diagnosis, there has been a hope that this will not be the determination. This definitive statement serves to announce that 'this is not over yet; there is more to come'. The fear of the unknown and the uncertainty are just beginning. The self-talk leads to questions about what lies ahead.

What am I going to do? Making decisions / Planning treatment

Once confronted with the pronouncement, 'yes, you have cancer', a person is bombarded with information about the 'usual treatment plan' for someone with a malignant bowel tumor. The necessity for surgical removal of the tumor as generally the first mode of treatment, leads to the expression of fears associated with undergoing any operation including: pain, anesthesia, lack of control, and the potential for complications. What will they find? The possibility of an 'ostomy is explored. As well, discussion of whether additional treatment measures will be required is initiated.

A familiar method of dealing with fears of the unknown is seeking relevant information. The surgeon is in the key position to provide much of the data, even though he or she has only recently met this person. An ability to highlight the central points and to relate this with an interpersonal style conveying genuine concern for the individual are invaluable attributes. Written material, including diagrams is helpful for both the presentation of facts and for subsequent review. Signing the formal consent form for surgery indicates the proclamation of "I am accepting this treatment."

There is an added challenge in talking to the individual in that, until the surgery is performed, the surgeon cannot be certain about what will be encountered. The location of the mass, the number of lymph nodes containing cancer cells, and the extent of tumor invasion of the bowel wall becomes highly significant. Waiting for the post-operative pathology report is a period of immense apprehension. What will they find? This crucial external pronouncement will guide the way to the next decision point about additional treatment possibilities.

Exploring one or more of a variety of complementary therapies for inclusion in the treatment regime is frequently contemplated. I wonder if anything else would help? The range of what is considered is extremely diverse, and extends from mental imagery, to the ingestion of certain herbs and substances thought to be effective in destroying cancer cells. Those who contemplate 'trying something different', may include discussion with the physician as part of their decision making process. When the physician is

opposed to the idea, the person usually adheres to the advice given as the physician is seen as expert.

Following the surgeon (or oncologist) specialist's pronouncement that treatment in the form of surgery, and/or chemotherapy, and/or radiotherapy is necessary, the individual then makes his or her own announcement regarding accepting the treatments. The process of making decisions related to treatments occurs more as an internal pronouncement by the patient, "I will do what they say is best." This is directly linked to and influenced by external pronouncements from the experts. Rather than deliberate consideration of the various options, the response taken most often is to accept the determination of the next action, as outlined by the physician. It is as though participants opt for direction from those who they perceive to have expert knowledge.

Prior to embarking on any treatment, most people express some degree of understanding of the rationale for the particular regimen. Alternatives have been explored. There is an awareness that others have been 'down this road' before, and that they are receiving recommendations from people who are the authorities. If the outcome of the surgery is formation of an 'ostomy', this is accepted as necessary. When the much less familiar territory of chemotherapy and/or radiotherapy protocols is introduced, for many, there is an even greater tendency to recognize the expertise of the physician and nurses. This trust in the expertise of the health care team leads one to hand over ones body to the care of those who know. Perhaps the self-talk that occurs is, "If I do this, then things will be okay."

Getting through it: Being treated

While the types of medical treatment: surgery, chemotherapy, and radiotherapy differ, there are commonalties within the experiences for the person who is in the receiving mode. Participants recognize that they are but one individual within the complex health care system. Their objective is to complete the treatment plan. "I will make it." The hurdles experienced with chemotherapy and radiotherapy are interpreted as obstacles to be overcome as one hopes for a cure.

Getting through treatment is marked by plodding along; forcing oneself to take one day at a time. There is a rescheduling of one's life. Even though choices are provided whenever possible, many customary activities are put 'on hold'. Details surrounding such items as the date of a certain appointment, the time of surgery, or the exact number of radiation treatments are recalled with great clarity. It is as though this experience is forever indelibly imprinted on one's mind. "I will never forget this." Appreciation for the technical abilities and knowledge of the health care workers implementing treatment strategies is paramount. Among the innumerable obstacles associated with chemotherapy and radiotherapy are the many common side effects. An attitude of perseverance is key as people encounter nausea, vomiting, and loss of appetite, sore mouth, extreme fatigue, diarrhea, and painful skin irritation. For some, enduring the unrelenting hurdles is a daily task. "I will get through this," but there are times when one wonders if he or she will be able to complete the treatments.

The individual works to "do what's best." Creating the best possible circumstances for treatment to be effective is a personal goal. There is a conviction that one's mental state has a profound and inextricable influence on one's physical health. A wide variety of approaches are used to attain the objective of doing all one is capable of in order to aid the healing process. These techniques include: keeping busy, consciously eliminating negative thoughts, reading books espousing affirmative messages, and including active exercise in one's daily routine. Theory about the role of the immune system as it relates to cancer, has been incorporated into the belief system of most participants. "I will do everything I can in order to aid my recovery." This type of internal pronouncement provides convincing personal support as they proceed with treatment. Along the way, people experience a great variety of kind acts, all of which help with getting through the treatments.

Receiving treatment encompasses the three conventional modalities. For some, this is relatively uncomplicated, involving only abdominal surgery. Others face the challenge of learning to cope with the intricacies of having a colostomy. Assistance from specialized enterostomal therapy nurses is essential to their success; success which may take several weeks to achieve. For those receiving chemotherapy, once the inaugural treatment anxieties are mastered, they proceed to adopt the point of view that all things are possible, "this too shall pass". Opportunities to become acquainted with others who are also having chemotherapy, provide a definite milieu of camaraderie. The supportive atmosphere plays a major role in assisting the individual toward

completion of the protocol. Radiotherapy treatments, even though occurring on a daily basis, do not afford the type of environment, which promotes such intimacy. Radiotherapy is more solitary. Even though it is inevitable that the cancer therapies are dominant in each person's schedule, individuals are also successful in maintaining segments of their normal routine. "I am trying to lead a normal life." Treatment agendas that included both chemotherapy and radiotherapy may extend as long as one year.

As each day of treatment is performed, individuals note this as a successful step bringing them closer to accomplishing the goal of completion. The external pronouncement that "today is your last day of treatment" is a vivid cue for celebration. However, for many, the prevailing feeling was a sense of profound exhaustion. When and how would they know if they had been successful?

What's ahead? Waiting and monitoring

While continual monitoring occurs throughout the treatment protocols, this activity acquires even greater importance at the conclusion of the formal therapies. The primary focus has been to achieve the goal; that is, to eliminate the cancer cells from the body. The greatest fear is that there will be a recurrence of the cancer. How does one determine the status of the disease that has entered one's body? Simultaneously, each person is vigilant in noticing those things that are normal for his or her body, and also in watching for changes which might indicate something unusual. "Which cues should I notice?" Individuals carefully note their bowel habits, as well as the attainment

and maintenance of a desirable body weight. Another critical observation relates to one's energy level or stamina for activities. The effect of ingesting certain foods, and the preservation of healthy sexual function are specific indicators for those with an 'ostomy'. Any sign or symptom that is not easily explained has the potential to become a source of concern. One speculates whether "things might not be okay. I wonder if the cancer is being controlled? Is it out of control?"

Regularly scheduled appointments at the cancer center provide a predictable routine for the commonly required surveillance tests and assessment by staff. Reminder cards are placed prominently where the notification cannot be missed. There is expanding knowledge of the significance of each test result and doctor's remarks. The individual is acutely attuned to each nuance of commentary related to his or her condition. With each follow up visit that is concluded with the external pronouncement, "Things look good," there is notable relief.

As the frequency of these visits diminishes, there is a feeling that the end is in sight. The end, that is, the internal pronouncement of 'I'm cured' may be when the person has completed the required treatments; or for others, the end will only be reached when he or she reaches (the magic) five years of being 'cancer free'. This phase of 'waiting and monitoring' leads to either a preferred outcome, or to a consequence that is not desirable.

Something is wrong... again: Starting over

For some, the proclamation, "There's no sign of the cancer," is not to be. Rather, there is a more gradual slide toward the recognition that, in spite of accepting the recommended treatment, the cancer cells are moving to other sites in the body. Once again, one must pay careful attention to bodily sensations. In these situations, there is a relentless cycle of one diagnostic test leading to another test, as more problems develop. The person must recommit to the whole cycle, yet again. Additional chemotherapy and radiotherapy treatment is provided, with widely variable degrees of success. The challenges of receiving both therapies concurrently seem even greater than before. One's life completely revolves around the requirements of treatment, and waiting for test results. Although recognizing the complexities of these cycles, it is also frustrating not to receive unequivocal announcements of success.

Trying to remain positive, in the face of recurrence of the disease, is an extreme challenge. Communications with family members change. Issues, put to the side by earlier successes, may need to be addressed. During this period of reappearance or return of the disease, some people choose to attend support groups. Diverse complementary therapies may be considered more often. As a person wonders "What are the alternatives to a cure?" there is a corresponding increase in dialogue about matters of spirituality. The phase of 'what's ahead: waiting and monitoring' is entered once again. It is

hoped that the ultimate pronouncement of "There is little more than we can do" is not to be heard.

Getting on with life: Reflecting / moving on

With the tentative early pronouncement of 'no cancer', each person engages in thoughtful reflection on a regular basis. This 'moving on', both figuratively and philosophically, is a way of thinking that permits one to separate oneself from the intense emotion associated with this diagnosis. A desire to have life events return to normal is paramount. The realization that this process might not ever truly be concluded is apparent.

One tries to understand why one has been diagnosed with bowel cancer. Such varied possibilities as one's age or genetic predisposition, as a result of dealing with a challenge, or as a response to pressure from excessive stress in one's daily life are explored. Having been able to live a reasonably long and healthy life prior to being diagnosed with colorectal cancer is acknowledged by many. The serious nature of a cancer diagnosis serves as a stimulus to make or to revise certain legal and financial arrangements. The pronouncement that 'one must attend to one's affairs' is viewed favorably, as something that needs to be completed regardless of outcome. Priorities are redefined.

Matters of spirituality take on particular significance at a time when one is encountering a life-threatening illness. Some express a strong religious faith; others adopt a more fatalistic viewpoint. The notion that 'having this

cancer' serves, as an impetus toward a particular purpose in one's life is prevalent, "Some good should come from this."

As individuals approach the conclusion of formal treatment regimens, there are frequent comments of a contemplative nature regarding thoughts of the future Views about how time might be spent, and what brings enjoyment for each day become paramount. Self-talk centers around "What will I do now?" "What is important in life?" Many thoughts entertained are of a very modest character: watching the birds, seeing family, or taking a short trip. Confronting the limitations of one's mortality, although expedited by the unanticipated circumstance of being diagnosed with colorectal cancer, is viewed as a positive element. The internal pronouncement focuses on the unexpected experience, which has resulted in a most beneficial process, or at the very least, one with surprising rewards.

Setting the context

The eight phases of this process occur within the context of two primary environments: the developing relationship with health care professionals and the sustaining relationship with family and friends. There are both favorable and adverse elements, in the interactions associated with these key relationships. By virtue of announcing 'knowing something is wrong', each participant initiates appointments with their family physician, which subsequently leads to a series of consultations with specialists in oncology. The relationships with family and friends vary considerably for each individual. There are those who have a very small number of friends or family

in the vicinity; others who have large numbers of supporters nearby. The majority feels bolstered by these relationships, although there are associated concerns.

Connecting with health care professionals

Both explicitly and implicitly, 'knowing something was wrong', leads to contact with numerous health care personnel. As each person proceeds on their unique experience, the number of new encounters increases. Physicians with a wide range of specialized expertise, and nurses who work in the health care facilities are most often mentioned as those who are instrumental in facilitating treatment and recovery. Noting personal names is reserved for the physicians; nurses and others are known more generically. Developing a relationship of trust requires the participant to form an impression derived from limited cues. Chief among those cues is the communication style of the health care professional and discernible signs of technical ability, leading one to feel 'in good hands'. The act of 'handing oneself over' to the experts is not undertaken casually. In some ways it is a form of 'blind trust'—how does the person actually comprehend with certainty anything about the quality of the care they are to receive? Allusions to one's vulnerability within the immense health care system are widespread. The role of each member of the health care is to engender the person's resolute belief in the capacity of the system to provide excellent care, as they undergo treatment for a colorectal malignancy. Team members have the potential to help or to hinder this process. An insensitive remark or bewildered facial expression has the

potential to instantaneously create concern in one who is ever watchful and wondering. Physicians, in particular, are viewed as persons of authority and power.

All forms of communication with health care professionals serve as a stimulus for the process of 'self-talk'. There will be pronouncements that are helpful and positive; there may be others that do not bring 'good news'. The actions and words of each team member are scrutinized carefully.

Experiencing support from friends and family

Support, for courage and moral fortification, is widely accepted as an integral component of the experience of living with bowel cancer. Those who provide the most fundamental help, in the form of instrumental behaviors and psychological bolstering, are observed to be family members, close friends, and certain volunteers. Activities, which serve as support, vary from person to person, and differ at the numerous stages of the cancer condition. Having the opportunity to talk about one's illness experiences with another individual who has had a similar venture is beneficial. The ability to discern what is supportive to someone is often based on extremely subtle observations, and even at times, on what not to talk about or what not to do.

The provision of social support, by one's circle of family and friends, has immense significance to each individual as they learn to live with colorectal cancer. 'Self-talk', with its internal pronouncements, is particularly influenced by the nature of ones social support. The external pronouncement from family and friends is "We are here to help you".

The theory that emerges from this study facilitates our understanding of the process of learning to live colorectal cancer. Figure 1 illustrates the theory. Although each aspect of this process are key there are four main areas that merit discussion. These include: the process of self-talk with its components of internal/external pronouncements, making decisions, the role of information, and support from health care professionals and family and friends. It is important to first place this substantive theory within the context of what is known about living with cancer and other chronic diseases.

DISCUSSION OF THE THEORY

How does the research presented here add to the literature and our understanding of the process of learning to live with colorectal cancer? Analysis of the data provided led to formulation of the developing theory, Self-Talk: The Inner Work of Illness. Self-talk is the basic social process used by an individual as s/he learns to live with colorectal cancer. Self-talk takes place in conjunction with an *internal* or *external pronouncement*, and stimulates the individual to take action. It is this central function of generating certain behaviors that is unique to the process of self-talk. Self-talk, thus, is not a passive process; it requires conscious and active thought by the individual. Although others have identified concepts such as 'inner dialogue' and 'hidden conversation' (Field & Marck, 1994), the view that internal and external pronouncements serve to initiate various activities has not been fully explored. In addition, what is key is that these internal pronouncements are shaped by many factors. One's own beliefs, values, and desires strongly

influence the interpretation of any external pronouncement, as well as the existence and type of social support one discerns. External pronouncements, in the form of information provided by health care professionals and significant others, carry much weight in relation to the internal pronouncements one makes.

Theoretically, self-talk, linked to internal and external pronouncements, may be viewed as parallel to Lazarus' (1966,1991, 1993, 1999), and Lazarus and Folkman's (1984) discussions and formulations of their psychological model of stress and coping. In Lazarus' seminal work he notes that "four environmental variables—namely, demands, constraints, opportunities, and culture—and the person variables that interact with them, influence our reactions via the *process of appraisal*" (1966, p. 61). Appraisal connotes an evaluation of the personal significance of what is happening (1999, p. 74). It may be then that 'internal pronouncements' are similar to the concept of 'appraisal', as they to lead to action. As well, self-talk occurs in response to cues from family, friends, and health care professionals. Similarly, Lazarus notes that 'appraisals are commonly based on many subtle cues in the environment, what has been learned from previous experience, and a host of personality variables' (1999, p. 81).

How one learns to live with colorectal cancer can certainly be viewed as a 'stressful life condition', and how one manages this circumstance may be described as 'coping'. Lazarus emphasizes that one of his main contributions to research and thought on coping is the notion of a *process* formulation

(1999, p. 103). This is consistent with the construct of self-talk as initiating actions and further reflection, within the trajectory of illness.

Additional support for the construct of self-talk is found in the work of Weinrach et al. (2001) and Ellis (1999). These authors, in their reviews of Rational Emotive Therapy, noted that persons actively talked to themselves both rationally and irrationally in order to maintain healthy, constructive tendencies and to overcome destructive counterparts.

In the descriptions of the experience of living with colorectal cancer, participants used various metaphors, such as 'being on a journey', 'ups and downs', 'the long road', and 'joining the club'. These metaphors are reflective of the self-talk that occurred. It may be that this is similar to what Meichenbaum (2000) notes with persons with posttraumatic stress disorder. He found that the language individuals use, the metaphors they employ, are important in how they appraise traumatic events and construct their self narrative.

Self-talk is depicted as occurring within an eight-phase trajectory that provides a framework for participant's experience as they learn to live with colorectal cancer. The notion of 'illness trajectory', first proposed by Glaser and Strauss (1968), has been observed by many in their attempts to understand how one learns to live with a particular chronic disease (e.g. Corbin & Strauss, 1988; Dorsett, 1992; Lubkin & Larsen, 1998; Morse & Johnson, 1991; Strauss et al., 1984; Woog, 1992). Although the labels attached to the various phases may differ, integral to each, as in this study, is

the notion that the course of the illness begins with some change in function and that the subsequent course has qualities of duration, movement, and shape. As well, work is done by both the individual and his or her family to shape and manage this trajectory. As first discussed by Corbin and Strauss (1988), this notion of work and the interplay between and among illness-related work, biographical work, and everyday-life work is evident in the data presented here. What the present study adds to Corbin and Strauss' perspective is the integral role that the healthcare team plays with their external pronouncements to that work and to the self-talk that occurs.

Attempts to understand how an individual comes to view him or herself as requiring professional medical assistance have been at the center of inquiry by many (Chrisman, 1977; Dimond & Jones, 1983; Kleinman, 1988; Mechanic, 1961, 1995; Parsons, 1951, 1979; Suchman, 1965). As Suchman notes in the early work on stages of illness and medical care, basic to the initiation of the medical care process is the perception and interpretation of symptoms. Similarly, Mechanic (1995) notes that whether a person identifies or recognizes a problem in the first place depends on whether he/she experiences some change that is regarded as undesirable or troublesome. It is this recognition of deviation that alerts the person to some problem. This seminal work holds true for participants in this study. However, what is difficult for people with bowel cancer is that the symptoms, such as constipation /diarrhea, are so easily attributable to other causes and, thus, are often seen as a "normal" outcome of other activities. So though the deviation is noted,

deciding that follow up by medical specialists is required, is often not straightforward. Potential meanings of symptoms are weighed and decisions are made as to whether the symptoms are normal. Again, similar to work by Suchman and others the person seeks "confirmation, advice, and reassurance..."(p.115). An appointment with the physician is key in confirming ones suspicions.

Once a person makes the internal pronouncement that 'something is wrong', several steps in the process occur. These phases may not be discrete in terms of time; often there is overlap of the permeable boundaries. For example, receiving the external pronouncement of the likelihood of a diagnosis of colorectal cancer is, of course, not definitive until the pathology review is completed. However, in the majority of situations, physicians (either the general practitioner or the surgeon) will share their clinical suspicion with the individual prior to surgery. As the general practitioner is voicing the possibility of "a tumor", the plan for surgical removal would be presented. Simultaneously, upon hearing the word 'cancer', a person may leap to thinking, "How long do I have to live?", truly not hearing the rest of the information presented. Similarly, the phase of *being treated* is inextricably linked with that of *waiting and monitoring.* During this period when *external pronouncements* are so critical, the individual also engages in simultaneous self- talk, creating *internal pronouncements* as part of the evolving process. It is at this time, that a person reflects on what this situation signifies and

decides how he or she will merge the new experience with that already acquired.

Confirmation of the significance of 'receiving the diagnosis' as a singular outstanding event is found in the work of Thorne (1993). Thorne discusses four distinct stages in the diagnostic process: the diagnostic testing process, the occasion of hearing the diagnosis, the meaning embedded in the diagnosis, and the impact of having received a diagnosis. These phases are observed in *Hoping for the best: Seeking diagnosis* and *Wondering about the future: Receiving the diagnosis*. Buckman (personal communication, March 22, 1995), in a discussion on giving a diagnosis, provides the analogy of 'breaking the bad news' as being similar to receiving a marriage proposal, one never forgets the details. In this study, participants shared this aspect of the process with great detail, noting the exact date and words when the pronouncement of "you have cancer" was made.

Jensen and Allen (1994) in their meta-ethnography of health-disease-wellness-illness and in their work on the categories inherent in wellness-illness (1993) note that various intra, inter, and extra-personal factors and cognitive and affective themes affect the patterning of perceptions of health-disease. Although not mentioned by Jensen and Allen, what was of note in this study was the influence of gender. Men tended to rely on their family, in particular spouses, to set the process of seeking a diagnosis in place, through acknowledging that the symptoms were of concern and reliance on the

spouse to make appointments for them. Women, in contrast, made their own appointments and frequently went to these appointments on their own.

One of the key cognitive factors addressed by Jensen and Allen was manageability; that is, the control persons have over events. Lack of manageability is noted to occur in times of uncertainty. As noted by Mishel (1990), and Mishel and Braden (1988) in the 'uncertainty in illness' theory, and Field and Marck (1994), in their synthesis of five studies related to childbearing, uncertainty is the inability to determine the meaning of events. It occurs when the decision-maker is unable to accurately predict outcomes because cues are lacking. The state of being uncertain leads to anxiety, worry, and, often impaired functioning. The lack of manageability and uncertainty was evident in this study in the turning over of self to the health care team, and the wondering about what was to unfold and its associated anxiety. Key to handling this uncertainty and unmanageability was the seeking of information.

In a classic review of the literature published between 1966 and 1986 (Northouse & Northouse, 1988), the importance of seeking information by patients, imparting information by health professionals, and acquiring information by family members was highlighted. Analysis of data from this current study reveals that the role of information remains paramount throughout the experience. In order to tell oneself that *something is wrong*, awareness of one's normal body functioning is the most salient feature. Although not specified by study participants, it may be that conscious

awareness of the early signs of cancer is operative at this time. Seven of the ten study participants experienced somatic changes that led them to initiate a visit to the doctor. This lack of routine screening is similar to the findings of Sarna and Chang (2000), who noted only about one-third asymptomatic older women had participated in early screening (FOBT or sigmoidoscopy) for colorectal cancer, most as a result of physician recommendation, not personal request. In addition, they noted that older women were unaware of the greater risk of colorectal cancer with increasing age (Landis, Murray, Bolden & Wingo, 1999).

The necessity for information continues as various treatment options are presented to the person with colorectal cancer, as observed in the phases of *being diagnosed, making decisions, planning treatment, being treated,* and *waiting and monitoring.* This observation is congruent with that of Wilson and Morse (1991), who found that one of the concrete strategies husbands of wives receiving chemotherapy used was gathering more information. Again similar to this study, Sahay, Gray, and Fitch (2000), in a treatment follow-up study, detected that "the majority of respondents felt they had been adequately informed about their treatment and its consequences, with some areas for possible improvement...concerns with lack of information about long-term management of the illness" (p. 40). Although it was not the purpose in the present study to discern satisfaction with information, the frequency with which the data focussed on 'information' was markedly noticeable.

It is the impact of *external pronouncements,* which is so unmistakable in the analysis of the present findings. Each *external pronouncement* is a strategic impetus propelling the person to another phase within the process. Although statements made by the medical oncologist carry the most impact, participants are also acutely attuned to the nuances of communication from others: nurses, radiation therapists, reception desk staff, immediate family members, friends, extended family members, even casual acquaintances. The common phrase of "You're looking well", takes on a whole new significance. At the various junctures, a participant hears the words of an *external pronouncement*, and observes the corresponding powerful non-verbal communication component. These elements of the *external pronouncement* then must be assimilated and discerned for influence on one's *internal pronouncement*. The *internal pronouncement* could include such thoughts as: "I'm doing well," "I should give this a chance," "She seemed to really mean what she said." It is the interplay between the *external pronouncement(s)* and the *internal pronouncement(s)* that is incorporated in the making of decisions throughout the trajectory. This is but one part of the 'work' of learning to live with colorectal cancer (Strauss, 1981; Strauss, et al., 1984). This work involves the taking in of information, in all forms, the interpretation related to this information, and, ultimately, deciding which actions one will undertake, as a person learns to live with colorectal cancer.

The process of decision-making by people with cancer has been studied extensively (National Cancer Institute of Canada, 1995) and is

inherently allied with the information provided, and the way in which information is communicated. As noted in the present study, the time period from *seeking diagnosis* to *being treated* (beginning with surgery) is usually a relatively short span, resulting in the person feeling besieged with information, as well as with a sense of urgency to make decisions quickly. The shock of a confirmed diagnosis, perhaps somewhat mitigated if the suspicion of cancer has been mentioned earlier, nonetheless impairs the person's receptivity and retention of vital information at this critical time. It may be that this is part of the reason one "hands oneself" over to the health care team.

The idea of 'handing oneself over' for treatment, identified in the present study, is in agreement with the work of several researchers (Degner & Russell, 1988, Degner & Sloan, 1992, Kutner, Vu, Prindiville & Byers, 2000; Llewellyn-Thomas, McGreal, & Thiel, 1990). In examining cancer patient preferences for control over treatment decision making, it has been noted that most newly diagnosed patients preferred that physicians make treatment decisions on their behalf (Siminoff & Fetting, 1991). Alternate choices included the concept of shared control, and active control, which have been observed with women who have breast cancer (Degner & Sloan, 1992). Similar to the findings by Sahay et al. (2000), participants considered the medical oncologist to be the primary source of information related to decisions around treatment, and clinical responses to treatment. In most cases, they relied on the oncologist to present all relevant information, and were somewhat hesitant to ask specific questions. In addition, older patients

tend to give more decision-making authority to physicians than do younger patients (Degner & Sloan, 1992; Kutner, Vu, Prindiville & Byers, 2000).

Kutner, et al (2000) compared patient and physician views regarding the question of patient age in relation to cancer treatment decisions, specifically in patients with stage III colon cancer. "Patient age is not recognized by patients or physicians as affecting the decision to use adjuvant chemotherapy. Other biologic and social factors are important, however, and the perspectives of physicians and patients differ regarding their relative importance" (p. 114). Physicians were more likely than patients to rank co-morbid conditions and the medical literature as important factors in making treatment decisions, while patients were more likely to rank physician opinion, family preference, and family burden as influential. Data from this research provide further evidence that information from physicians is a major influence for individuals as they decide how to proceed. In addition, the significance of the impact of personal decisions on family members is also considered.

Patient perceptions of treatment side effects influence their decisions about participating in adjuvant therapy. Lindley, et al. (1999) found that "noncancer, chemotherapy-naïve patients perceived most chemotherapy-associated side effects as having greater impact on the quality of life than did cancer patients who had received chemotherapy" (p. 59). In other words, when a person is first presented with the idea of chemotherapy, he or she may have the greatest concerns and the least accurate understanding. People often make treatment decisions based on incomplete or incorrect

information (Sutherland, Llewellyn-Thomas, Lockwood, Tritchler & Till, 1989). Another investigation revealed that many patients decide to consent or refuse to participate in a cancer clinical trial during the first visit to the oncologist (Huizinga, Sleijfer, van de Wiel, & van der Graaf, 1999), thus "raising questions about the normative quality of the decision" (p. 119). . . . "They may have arrived at their decision on the basis of intuitive factors such as concern and fear, hope, and (anticipated) decision regret" (p. 124). These findings were substantiated in the current study when one participant chose not to take chemotherapy based on awareness of earlier experiences of someone she knew.

Even with the occurrence of treatment side effects, living well with one's disease, was the focus of much of the 'self-talk' by participants in this study. This self-talk resulted in convincing *internal pronouncement* that "in spite of side effects, I believe that the treatments are making a difference, and I will continue". Again this self-talk was greatly influenced by the information giving and reinforces the importance of the appropriate timing of providing comprehensive information on treatment side-effects such as cancer-related fatigue (Curt, 2001;Holley, 2000; Nail & Jones, 1995; Winningham, Nail, Burke, & et al., 1994), or of the impact of some forms of cancer treatment on areas such as sexual functioning (Gallo-Silver, 2000). As well, similar to the findings of Klemm, Miller and Fernsler (2000) in their work on the most common and intense demands of illness in people with colorectal cancer, the

highest demands were found to pertain to symptom monitoring, treatment-related issues, and to the personal meaning of the disease.

Throughout the self-talk of *'getting through it: being treated'* and *'what's ahead: waiting and monitoring'*, participants seek to lead as normal a life as possible, trying to minimize the role of being a patient or a sick person. Strauss (1981) noted the business of the chronically ill is to live as normally as possible, despite the symptoms and the disease. The personal reflection, and desire to 'move on', as noted in the present study, confirms observations made by other researchers of various threats to health (Chasse, 1991; Hilton, 1996, 2000; Johnson, 1988; Lorencz, 1991; Tishelman & Sachs, 1998; Wilson & Morse, 1991). In particular, Hilton (2000) noted that 'focusing on family to keep life going' was one of two major themes that men use in coping with their wife's breast cancer. Changing priorities and living one day at a time are mentioned often by those who have experienced the diagnosis of a life-threatening disease.

Specific work looking at the process of learning to live with cancer has been undertaken by Dorsett (1992) as well as others (Hilton, 2000; Thorne, 1986; O'Connor, Wicker & Germino, 1990). Dorsett, conceptualized a 'trajectory of cancer recovery' as a preferred model, proposing cancer be considered as yet, another, chronic illness but not always one with a downward spiral. In addition, much work has been done in the area of 'cancer survivorship' (Dudas, & Carlson, 1988; O'Connor & Wicker, 1995; Welch-McCaffery, 1988). This approach to cancer as a chronic illness informs, and is

consistent with the current study. As statistics illustrate (National Cancer Institute of Canada, 2000), the majority of people diagnosed with the most common cancers (prostate, breast, lung, colorectal) do not immediately proceed to a dying phase; people are living longer with a cancer diagnosis. The ten participants of this report were actively engaged in their lives; receiving treatments or attending the cancer clinic for 'tests', were important events, but these did not constitute their whole life. The goal was to recover.

The importance of social support from health care professionals, and from family and friends has long been recognized as contributing to the success of living with chronic disease (Caplan, 1976; Cassel, 1976; Cobb, 1976; Lazarus & Folkman, 1984; Norbeck, 1988; Stewart, 1993). Cobb (1976) states social support would lead a person to believe (1) that he or she is cared for and loved, (2) that he or she is esteemed and valued, and (3) that he or she belongs to a network of communication and mutual obligation. The intimate relationship of social support to achieving and maintaining health is a commonly accepted belief. Some researchers have emphasized that social support has a direct relationship to health so that the person who has support is less likely to become ill; others have noted that adequate social support can minimize the harmful effects of stress on a person's mental or physical health (Spiegel, 1989).

Study participants, living with colorectal cancer, made extensive references to two primary sources of support: *family and friends* and *health care professionals*. The notion that *support from family and friends* is a critical

factor as one learns to live with colorectal cancer is not a new idea, but the present findings reemphasize the importance of this role. Similar observations have been noted in studies of people diagnosed with other common types of cancer (Hilton, 2000; Kristjanson & Ashcroft, 1994; Lewis,1990; Northouse & Northouse, 1988; Thorne, 1985). Whether it is the encouragement from one's spouse to make the doctor's appointment; the regular visits to the hospital following surgery; words of comfort via cards and notes; or the assurance that it is 'okay' to take a nap when one is receiving radiotherapy, *social support from family and friends* is integral to the process of self-talk, and the internal pronouncements that are made. How an individual frames the *internal pronouncement* may well hinge on perspectives linked to the presence (or absence) of social support.

Similarly, knowing well the impact of receiving an *external pronouncement* of, "Yes, the tests do show bowel cancer', is instrumental in health care professionals being perceived by participants as true 'caregivers'. How a nurse conveys caring to a person has been the subject of innumerable studies (e.g. Benner, 1984; Benner & Wrubel, 1989; Davies & Oberle, 1990; Halldorsdottir & Hamrin, 1997; Koopmeiners, et al, 1997; Larson, 1984, 1986). The notion of 'connecting', or 'getting in touch with' the patient and family members, that is, entering their experience, (Davies & Oberle, 1990; Jenny & Logan, 1992; Webb & Hope, 1995), is but one aspect of the contextual 'relationship with health care professionals'. 'Being with' the person who is living with colorectal cancer, is a complex, and essential requirement

in order that the individual experience support from those in the health care system. As well, the interconnection between 'information' and 'communication' are important observations of this study. As Thorne (1999), advocating for qualitative study for evidence-based practice, states: "Beyond the body of knowledge related to cancer consultations, quality of life, and professional skill development, some recent efforts have attempted to broaden the research-based understanding of the impact of communication in cancer by examining its relationship to much less concrete outcome measures" (p. 371). What was clear in this study was that it is not only the content of the message given that is contemplated, but also the way in which the content is delivered.

This study on the process of learning to live with a diagnosis of colorectal cancer contributes to evidence-based nursing practice, with the identification of four primary areas for consideration: the process of self-talk with its components of internal/external pronouncements, making decisions, the role of information, and support from health care professionals and family and friends. How these areas may impact the provision of expert nursing care and future research will be discussed in the next chapter.

Chapter 6

IMPLICATIONS FOR PRACTICE AND RESEARCH

Nursing Practice

The findings and subsequent developing theory from this research lead to numerous implications for nursing practice. It is possible that observations made will also be applicable to those in related health care disciplines. Foremost from the theory, nurses must be very aware that there is a process of self-talk that consistently occurs for individuals who are diagnosed with colorectal cancer. For each person, there will be vitally unique aspects to both the *internal* and *external pronouncements* that occur. As well, a considerable part of this self-talk takes place within the person; inner-dialogue that is, for the most part, inaccessible to the health care professional. As the phases inherent in the process of living with colorectal cancer are not isolated or discrete, there is back and forth movement between them and as a consequence aspects of self-talk reoccur.

The significance of the process of self-talk is noted most predominantly at particular trajectory junctures; when one knows something is wrong, receiving the diagnosis, making decisions/planning treatment, and while waiting and monitoring. *Knowing something is wrong* does not automatically prompt a person to seek verification or assessment. Nurses must be ever vigilant for opportunities to provide education regarding what might be considered normal and what might not be considered normal. Societal norms

tend to preclude talking about colorectal cancer. Nurses can play a lead role in unveiling these discussions. The media have played a significant role in educating the public about issues related to breast, prostate, lung, and skin cancers. Similarly, efforts must be made to raise the level of general knowledge with regard to colorectal cancer. Since colorectal malignancy is more commonly found in individuals over the age of 60 years, it is important to target this particular population sector with relevant information. Encouragement to *seek diagnosis* can come from the nurse.

The *external pronouncement* of *receiving the diagnosis* retains a strategic position in the trajectory/self-talk schema. One must not underestimate the significance of this occasion. The nurse must make every effort to be with the person when the diagnostic information is being conveyed. S/he will be required to help 'fill in the gaps' once the 'shock' of the announcement dissipates, ever so slightly. The specifics of this help can include everything from providing comfort, clarification of medical terminology and statistics, to helping the person figure out 'what's next'? In some ways, the nurse's role during this phase is more a 'being with' rather than 'doing to' (Bertero, 1999).

The process of *making decisions* for the purpose of *planning* cancer treatment has been recognized as a critical element for patients. The nurse must understand the theory that is proposed to explain this facet, and then, seek to support individuals who are at this point of the trajectory. If one realizes that many people will tend to 'hand over' the decisions surrounding

treatment to the physician, then the nurse is in a strategic position to ensure that the individual receives the most helpful information. The judgment of what is pertinent is not a simple task, as requirements will vary considerably from one person to another. Acknowledging this ever-present uniqueness may be advantageous to the nurse, as s/he assists in this process. The nurse needs also to remember that the patient has a different perception of time, in that there is often a 'sense of urgency' described around this phase. Thus, as much as possible, the person should be given a period of time in which to acquire information, and to make the decision about accepting (or rejecting) treatment recommendations.

The nurse's role in supporting the person with colorectal cancer during the *waiting and monitoring* phase is not well delineated. Since this phase occurs both during the '*being treated'* stage, and also, for several years following, the type of support may change considerably during this time span. Acknowledgement of the emotional 'roller-coaster' effect of attending the cancer clinic for surveillance must be provided to all. Thorough documentation of the individual's activities of daily living, any changes, concerns, and questions is essential, in order to provide appropriate assistance and guidance. As much as possible, continuity of personnel should be the aim, so the person has an increased sense of familiarity with the routines and procedures.

As a person continues on the 'recovery' trajectory, there is much self-talk of a reflective nature, particularly as one '*moves on'*. A key element of this

self-talk is the individual's endeavors to live as normal a life as possible. Thus, it is important that the nurse help the person to make the diagnosis and treatment of cancer as just one aspect of their life. As well, accentuation of the good things that are happening is regarded as more effective to attaining the goal of survival.

In understanding the flow of self-talk that occurs between internal and external pronouncements, the role of information is primary. It is largely on the basis of information, of all types, that the individual determines the next step. The nurse is a vital source for this knowledge. Currently, the majority of information is provided verbally, and often, only given to the one person, the identified patient. Encouraging another person to attend appointments to also receive the information would be beneficial. Tangible forms of media could be implemented such as print, audio material, and computerized resources. The possibilities of providing a group format for discussion of common issues needs to be assessed.

Not only the 'what' of that which is imparted, but also, the 'how' it is communicated is so vitally important. The nurse needs to convey that s/he cares about the individual living with colorectal cancer. S/he needs to take time and make the effort to really know the person, both the body and the biography. Listening to the words, and attending to the nonverbal aspects of communication with the individual is key. As well, the environment provided for interaction must be conducive: private, pleasant, and quiet. Perhaps in these ways, the nurse will come to learn more about the content of the

internal pronouncements that are so influential. In so doing, s/he will be more able to respond to the 'real' questions.

Throughout these stories are many examples of the coping strategies that participants used to navigate their experience through each phase. It is incumbent on the nurse to explore these coping strategies, and where necessary, to teach other ways to work through the challenges with which these people are confronted.

In addition to the implications for the nurse in relation to key points along the self-talk trajectory, recognition of the *support* provided by the family and/or friends is critical to consider. In reality, the unit of care is not only the person, but the person and his/her family. Particular acknowledgement of the role of the family (friends) early on in meetings, and encouraging some member to regularly attend with the patient, will greatly facilitate the nurse's ability to provide support to them. In turn, the additional person will be that much more able to act as a support to the individual who is living with colorectal cancer.

Nursing Research

Given that there is a lack of nursing research on any aspect of living with colorectal cancer, the entire field would benefit from additional investigations. In relation to the process of self-talk, one can question if there are subtle or significant differences on how this process unfolds based on gender and age.

More data on the significant factors in 'knowing something is wrong' would contribute to answering the question of how to communicate to the general public about early detection of this type of cancer. As increasing consensus is reached regarding the form for screening for colorectal cancer, how best to educate the target audience will require study. Determination of the preferred methods of providing information, the type of information most relevant, and the optimum time period, from 'receiving the diagnosis' to 'making decisions' regarding treatment are all key questions for subsequent research.

With those individuals who are advised to undergo adjuvant therapies, there is a whole new range of research possibilities. Since most treatment protocols for colorectal cancer occur over the time span of several months, and particular side effects can be predicted, how a person copes with these events or sensations merits examination. In particular, the phenomenon of fatigue has not been studied extensively with people living with colorectal cancer. Nor has the role of exercise as therapy been addressed in an organized manner.

Since the goal of most individuals undergoing treatment for bowel cancer is to recover and move on, not merely to survive, the impact on one's quality of life needs to be studied. What are the long-term effects – both physical and emotional, following diagnosis with colorectal cancer?

Consistent with the methods of Chenitz and Swanson (1986), the use of constant comparative analysis and theoretic sampling led to the

participation of particular individuals. Due to certain gate-keeping activities in the cancer centre, as observed in chapter 3, it was not possible to do full theoretical sampling for additional data gathering. For this reason, it may be prudent to consider this theory as tentative. In reviewing the characteristics of this group of ten people, it is noted they are predominantly of Caucasian origin, with some level of post-secondary education, and from primarily, a comfortable socioeconomic range. It is possible that their responses are not similar to those of people of differing circumstances. On the whole, the sample was representative of the population, and did include someone younger than the norm.

In this study, while all participants engaged in 'self-talk', the matter of 'degree or amount', varied. For some, 'self-talk' was particularly dominant; for others 'self-talk' was less extensive. With more extensive data gathering, it might be found that some people do not engage in 'self-talk'. As well, participants were asked to 'tell the story' of their experience while living with colorectal cancer. Of necessity, this was a retrospective gathering of the data. Each person could select those aspects that s/he wished to divulge to the researcher. By the same token, the individual could also decide not to discuss any matter of their choosing. In essence, this was a form of cross-sectional study, in that all data were collected within approximately a one-year period. More longitudinal studies may provide other, unique data. One might wonder if 'self-talk' continues at the same pace, diminishes over time, or is associated with particular personality types. Does self-talk mean an ongoing dialogue

with oneself, or does it also include random thoughts? What is the role of language in expressing self-talk?

Given the lack of previous studies of people living with colorectal cancer, there are significant opportunities for nursing research. As future research is conducted, an important focus must be on the development of effective nursing interventions for this group of individuals. It is only then that we can make a difference to the lives of people who are living with colorectal cancer.

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Appendix A
Information Sheet

Project Title: **LIVING WITH COLORECTAL CANCER**

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This research study is being conducted by a student in the doctoral nursing program at the University of Alberta. The purpose of the study is to find out how a person learns to live with the diagnosis of colorectal cancer. You will be interviewed two to three times by the researcher. The researcher will ask you questions about living with cancer, your early knowledge about cancer, what is helpful to you, and what is less helpful to you in learning to live with colorectal cancer. You can refuse to answer any question you are asked. Each face-to-face interview will last about one to one and a half-hours, and will be audiotaped. You will not need to be in the hospital or clinic to take part in this study. Interviews will be set for a time and place that is good for both you and the researcher. These interviews are not a standard part of care for patients with colorectal cancer.

Information gathered in this study will be kept strictly confidential. Your name will not appear anywhere in the study. Numbers will be written on the interview tapes instead of your name. Only the researcher will know your

name and which code number it is given. A secretary will listen to the tapes and make typed copies of the information. Other people helping with the study may read the typed copies or listen to the tapes. These people will not know who the participants are and will not share the information with anyone. The researcher will not discuss your problems and concerns with other health care personnel unless you agree.

All information will be kept in a locked file during the study. Only the researcher will have a key. The consent forms will be destroyed after five years; the tapes will be erased after seven years. A report of the study will be written and the findings will be shared with others. Some of the your words may be in the report but your name will not be used. There will be no way of knowing who the participants are. The data from this study may be used in future research but only if an ethics committee gives approval.

Taking part in this study will not result in any health risks or extra costs for you. If you feel upset during or after an interview, you can call the Department of Psychosocial Resources at the Tom Baker Cancer Center at 670-1767. Someone there will talk to you about your feelings. Taking part in this study may be of no personal benefit to you. However, based on the results of this study, it is hoped that, in the long-term, patient care can be improved.

Your doctor has consented for you to be approached to take part in this study. The final decision, however, is entirely up to you. You are free to choose not to take part in this study. If you decide to take part, you can leave

the study at any time by telling the researcher of your wishes. You can also ask her to leave any information out of the study report. Your care will not change as a result of any of these actions or choices.

If any knowledge becomes available that could influence your decision to continue in the study, the researcher will notify you immediately.

_____ _____

Patient's Initials Date

Letter for Mail Contact

Dear Sir or Madam:

I am sending you information about a research study called "Living with Colorectal Cancer". I am a doctoral student in nursing at the University of Alberta. I have practiced as a nurse and nurse educator for 25 years in Calgary.

I am looking for people with colorectal cancer who might like to take part in the study. Please read the Information Sheet and decide whether you would like to hear more about the study. If you are willing to have me contact you, please complete the contact form and return it in the enclosed envelope. Returning this form does not mean you have to take part in the study. It simple means that I will call you to talk with you about the study and answer your questions. If you return the contact form, expect a telephone call within about two weeks.

Thank you for your time and for considering participation in this research study.

Sincerely,

Marilyn Will, R.N., B.Sc.N., M.Ed., PhD (C)
Graduate Student
Faculty of Nursing
University of Alberta

for

Dr. Keith Arthur
GI Tumor Group
Tom Baker
Cancer Center

Contact Sheet

LIVING WITH COLORECTAL CANCER

I would like to hear more about the research study called "Living with Colorectal Cancer". The researcher may call me at the number below.

Name:_____ Signature:_____

Address:_____

Phone number:_____ Best time to phone: _____

Consent Form

Project Title: **LIVING WITH COLORECTAL CANCER**

Principal Investigator:

Dr. Keith Arthur
Researcher, GI Tumor Group
Tom Baker Cancer Center
Office phone:
(403) 670-2012

Marilyn Will
RN, BScN, MEd,
PhD (Candidate)
Graduate Student
Faculty of Nursing
University of Alberta
Phone:
(403) 242-9139

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more details about some area mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand the information.

Purpose of project: This research study is being conducted by a student in the doctoral nursing program at the University of Alberta. The purpose of the study is to find out how a person learns to live with the diagnosis of colorectal cancer.

Study procedure: You will be interviewed two to three times by the researcher. She will ask you questions about living with cancer, your early knowledge about cancer, what is helpful to you, and what is less helpful to you in learning to live with colorectal cancer. You can refuse to answer any question you are asked. Each face-to-face interview will last about one to one and a half hours, and will be audiotaped. You will not need to be in the